Transformative effects of social media:

How patients' use of social media affects roles and relationships in healthcare

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Chapter 1: Introduction

1.1 General introduction

Back in 1998, Stephen Heywood, then at the age of 29, was diagnosed with a rare disease, Amyotrophic Lateral Sclerosis (ALS). Given that it is a rare disease, he and his family found it challenging to find information about the disease, particularly about experiences of others who had the same disease. To help him, in 2006, his brother and his friends launched the social media platform called PatientsLikeMe to connect with other ALS patients and help their brother/friend. However, by 2011, the platform itself grew so much that they opened it to all patients with different conditions. Today, PatientsLikeMe has over 600,000 users with more than 2,800 conditions, allowing these patients to share their knowledge and experiences. PatientsLikeMe has also grown into a thriving business cooperating with the pharma industry and changing the traditional ways of doing pharmaceutical business (Wicks, Vaughan, Massagli, & Heywood, 2011). Moreover, such a platform organizes patient participation in a way that breaks the strong expert culture of medical practice by providing an opportunity to patients to enter data unsupervised, thus capturing details of patients' lives that were traditionally outside traditional medical research (Kallinikos & Tempini, 2014).

The example of PatientsLikeMe illustrates the increasing use of social media in healthcare and identifies potential changes that may arise for different actors regarding their roles and relationships. By social media, we mean Internet-based applications built on Web 2.0, which enable the creation and exchange of user-generated content (Kaplan & Haenlein, 2010). Since their emergence in 2004, social media have been changing how we communicate, collaborate, and build knowledge (Aral, Dellarocas, & Godes, 2013). Social media have even transformed entire industries such as newspaper publishing and retail (Byers, Mitzenmacher, & Zervas, 2012; Kwak, Lee, Park, & Moon, 2010). Healthcare is no exception, and these new technologies allow different ways to conduct research and build knowledge, which can eventually change

healthcare (Topol & Hill, 2012). In this line, we have seen a high proliferation of social media in healthcare (Kane, Fichman, Gallaugher, & Glaser, 2009). It also corresponds to generally high interest in online health information. For example, in the United States of America (USA), 72% of adult internet users looked for health-related information online (Fox & Duggan, 2013). Patients often look for this on social media sites hoping to find support from others (Lee & Kvasny, 2013). Accordingly, Information Systems (IS) scholars have called for extending research on social media in healthcare (Agarwal, Gao, DesRoches, & Jha, 2010; Fichman, Kohli, & Krishnan, 2011). In particular, one of the issues the scholars have called for new research to focus on is the role of patients in using social media, and subsequent effects of social media use on offline processes of healthcare (Agarwal et al., 2010; Fichman et al., 2011). Thus, in this dissertation we focus on these specific topics. In line with this, our research aim is to explore the use of social media by patients, the related effects on patients and their roles, on their relationship with their healthcare providers, and on healthcare providers themselves. By patients, we mean users of social media for health-related purposes and by healthcare providers, we mean those who provide medical care for patients (i.e. general practitioners and medical specialists). In the sections below, we elaborate on specific research gaps related to this aim and the way we address them. Each chapter in the dissertation represents a paper that has either been published in a journal, presented at an academic conference or is in the process of being submitted to a journal. Thus, as each chapter is also a standalone paper, there may be some overlap between chapters in terms of the summary of background literature.

1.2 Systematic review of extant literature

Social media have changed how we communicate and conduct business (Aral et al., 2013). Recent empirical evidence suggests that the social media even redefine entire industries such as news publishing and retail (Byers et al., 2012; Karimi & Walter, 2015). In line with these general trends, healthcare is also experiencing an increasing number of patients who are using

social media for health-related purposes. In line with this, academic attention to these topics has also increased, and there is some literature showing that patients are using social media for social support and this use may affect their behavior (Hawn, 2009; Ho, O'Connor, & Mulvaney, 2014; Rupert et al., 2014). To reflect on this increasing trend and to set the ground for our empirical chapters, we first focus on providing a general overview of the extant literature. To do so, we follow our main research objectives and conduct a systematic literature review on patients' use of social media and changes in the relationships between patients and healthcare providers from the patients' and the providers' perspective. Accordingly, in our chapter two, we address our first research question as follows:

What are the effects on patients from their use of social media and how does this influence their relationship with healthcare professionals as reported in extant literature?

1.3 Taxonomy of social media enabled interactions in healthcare

In chapter three, we examine how patients are using social media and provide a categorization of this use. Patients and organizations have used social media for informing, supporting, advocating and fundraising (Lapointe, Ramaprasad, & Vedel, 2014). It is particularly evident that the patients increasingly rely on the Internet and specifically on social media to search for health-related information (Fox & Duggan, 2013). Recent studies confirmed that the use of social media by patients is gaining in importance and prevalence (Zhao, Ha, & Widdows, 2013; Ziebland & Wyke, 2012). The reason is that it enables patients to access health-related information, to interpret it, and to contribute their own experiences for the benefit of themselves and others (Adams, 2010). As a result, patients can find relevant information and feel supported (Ziebland & Wyke, 2012). They can also increase their knowledge and exchange advice (Antheunis, Tates, & Nieboer, 2013), feel empowered (Johnston, Worrell, Gangi, & Wasko, 2013), and make more informed decisions (Wicks et al., 2010).

Patients rely on diverse social media categories such as Facebook, Twitter, YouTube and specific social media platforms. Social media platforms can be initiated by patients (Van Der Eijk et al., 2013) or by doctors (Van de Belt, Berben, Samsom, Engelen, & Schoonhoven, 2012). There are many different forms of social media use related to healthcare, which is sometimes illustrated through various terms used in the literature such as social media health communities and online patient experiences (Wicks et al., 2010; Ziebland & Wyke, 2012). As a result of the fast pace at which health-related social media are developing, there is no clear overview of how patients make use of social media and how their interactions can be categorized, which is essential for more in-depth understanding and exploring effects of such use. Thus, we aim to explore the use of social media by patients and propose the first taxonomy of social media interactions by patients, which will clarify the types of interactions between different actors on different categories of social media. Thus, we address our first empirical research question in chapter three, namely:

What are the typical interactions in health-related social media and how can we categorize them in taxonomy?

1.4 Effects of patients' social media use on their relationships with other patients and with their healthcare providers

In our three remaining empirical chapters, we focus on the use of social media by patients and the related effects on their roles as well as the roles of their healthcare providers, specifically doctors. In fact, the relationship and interactions between patients and their healthcare providers are often deemed as one of the most important activities that healthcare providers carry out in their patient-related work (Reay, Goodrick, Waldorff, & Casebeer, 2017)

Nowadays, social media are shaping patients' interactions by redefining social ties (Coiera, 2013). As described in the introduction, PatientsLikeMe is an example of a healthcare platform that enables information sharing and aims at transforming how patients manage their conditions

and change the way industry conducts research (Kallinikos & Tempini, 2014). Early after the introduction of social media, it has been suggested that social media may have an impact beyond the patients themselves (Johnson & Ambrose, 2006). Though healthcare has been traditionally managed mostly through interpersonal communication between the healthcare provider and patient, social media offer new modes of interaction. Different types of interactions (e.g. with caregivers, other patients) may shift healthcare away from a primarily professionally led process of disease management to a social phenomenon involving experiential knowledge. The role of a passive patient who simply receives doctor's advice and care may be challenged when patients give more credibility to online information than to their doctors (Agarwal et al., 2010). This may be the case for several reasons. Firstly, social media change the way patients can access and share information, which reduces earlier information-asymmetry where patients had to rely on their doctors (Arrow, 1963). Access to social media provides them with the opportunity to build knowledge independently, challenging the status quo in the healthcare system regarding information provision (Fichman et al., 2011). Secondly, communication through social media, as opposed to offline communities, offers patients the ability to easily make contact with fellow patients they would otherwise never meet. Such interactions offer new routes to behavioral change and allow people to make health-related decisions differently (Wicks et al., 2010). In this way, social media may lead to changes in the relationship with healthcare providers and their roles in the healthcare system (Andersen, Medaglia, & Henriksen, 2012). While extant literature proposes that social media may be changing the relationship between patients and their healthcare providers, it remains unclear how this takes place and affects patients and their healthcare providers. Therefore, it is necessary to understand when and how social media change this relationship. We explore this through three chapters from patients' and doctors' perspective. Accordingly, we address three research questions as elaborated further in the sections below.

1.4.1 Changing roles of chronic diseases patients

In our chapter four, we focus on chronic disease patients' use of social media and changes in their roles, and their relationship with each other and with their healthcare providers. As noted in the introduction, social media use enables patients to come together, communicate, share knowledge, and even sometime self-manage their condition (Lederman, Fan, Smith, & Chang, 2014; Merolli, Gray, Martin-Sanchez, & Lopez-Campos, 2015). Such development could change roles and identities of patients (Fox & Ward, 2006), for example, Agarwal et al. (2010) suggest that this could change their roles in relationship with healthcare providers. Furthermore, social media can impact one's construction of identity (Zhao, Grasmuck, & Martin, 2008). This is particularly important for chronic disease patients because their lives and identities can be significantly affected by the disease (Asbring, 2001). Opportunities afforded by social media represent a new avenue for the management of chronic diseases and the development of partnerships between patients and their healthcare providers (Seeman, 2008). Yet, this relationship is characterized by a high-level of information asymmetry and providers' central role in giving medical advice and a high degree of authority (Offenbeek, Boonstra, & Eseryel, 2012; Reay & Hinings, 2005). Furthermore, patients' perspective and impact of social media on their roles has received limited attention (Agarwal et al., 2010). To tackle this, we take patients' perspective and focus on patient roles and identity, addressing the following research question: *How does social media use by chronic disease patients afford changes in their identity and their roles in relation to healthcare providers?*

1.4.2 Use of social media by patients and changes in doctors' occupational identity

To address our following research question, we extend our research endeavor to include doctors' perspective in our chapter five. In particular, we draw on occupational identity theory to explore how the use of social media by patients affects doctors' occupational identity, specifically an aspect of "what they do" to their identity (Ashcraft, 2013; Nelson & Irwin, 2014;

Pratt, Rockmann, & Kaufmann, 2006). This aspect of identity is concerned with showing how professionals tend to explain how they see themselves in terms of what they do and how they distinguish themselves from other occupations. The role of professionals such as doctors has always been emphasized as an important role and they enjoy high levels of autonomy in society (Larson, 1977). Yet, public sectors have been experiencing some changes in terms of creating new forms of professionalism (Noordegraaf, 2007). This is particularly the case in healthcare where research on the roles of doctors has attracted significant attention (Goodrick & Reay, 2010, 2011; Pratt et al., 2006). In healthcare, the roles of doctors as professionals can basically occur in two ways. Firstly, through taking an oath and proclaiming a public commitment to the profession of a doctor and, secondly, through daily interactions with other actors in healthcare (Pellegrino, 2002). The focus of our chapter is on latter, particularly on the interactions with patients as one of the most important aspects of a doctor's work (Gottschalk & Flocke, 2005).

Our research in this chapter contributes not only to the literature on healthcare information technology but also on the topics of technology and occupational identity. Extant literature on occupational identity and technology has mostly focused on the aspect of "who we are". Thus, the scholars have offered less attention to the question of "what we do" (Nelson & Irwin, 2014). Earlier studies in this stream of literature have indeed shown that technologies can affect occupational identity. For example, Leonardi (2007) indicated how roles of IT technicians change as a result of information from technology. However, the core of how occupational identities get shaped does not lie in an individual's interactions with the technology itself. Identities are relational and strongly embedded in interactions (Vough, Cardador, Bednar, Dane, & Pratt, 2013). Thus, roles and identities are enacted vis-à-vis others through interactions (Langley et al., 2012). This is also the case in healthcare where the identity of doctors is shaped in interactions with different actors (Reay et al., 2017). For example, Reay, Golden-Biddle, and Germann (2006) showed that the changes in the roles of nurse practitioners included

interactions with other health professionals. Although the concept of occupational identity and in particular the question of "what we do" is strongly relational and embedded in interactions with others, extant literature has somewhat ignored this (Reay et al., 2017). In this respect, we address our following research question as follows: *How does the occupational identity of doctors in terms of "what we do" change as a result of social media use by patients?*

1.4.3 Role of self-determination perspective in explaining the relationship between patients and healthcare providers

In chapter six, we draw on the self-determination perspective to test to what extent different types of social media use for health-related purposes affect the relationship between patients and their healthcare providers. Earlier literature has made either proposition or has not provided a mechanism through which changes in the relationship between patients and their healthcare providers take place (Rupert et al., 2014). Furthermore, many of the previous studies on online health strongly focus only on the role of informational support as a way to build knowledge and initiate changes in the treatment of the disease (Koetsenruijter et al., 2016) or potential change in the relationship with healthcare providers (Rupert et al., 2014). In this chapter, we focus on emotional and informational support as two most common forms of social support. We explicitly draw on the psychological perspective of self-determination to hypothesize direct effects of emotional and informational support on the concepts of self-determination and indirect effects on the relationship between patients and healthcare providers. The self-determination perspective has a strong potential to explain healthcare-related outcomes (Ng, 2015). This is the case because many health-related outcomes depend on an individuals' motivation to engage in the necessary health-related behaviors (e.g. physical activity, taking medicines and following a diet). This perspective helps by explaining whether an individual will internalize and integrate the necessary health-related behaviors, and ultimately, whether a person will be motivated to engage in the behaviors (Ryan, Patrick, Deci, & Williams, 2008).

We build our hypotheses using fundamental concepts from this theoretical perspective. In this way, we address the following research question: *To what extent does social media use by patients affect their self-determination and indirectly affect their relationship with healthcare providers?*

Chapter 2. Effects of social media use by patients on their behavior and relationship with healthcare professionals: A systematic literature review[1]

Abstract

Patients are increasingly using social media for health-related purposes. To reflect on this trend, we provide an overview of the extant literature on the effects on patients from their use of social media and the influence on their relationship with healthcare providers. We conducted a systematic literature review to identify the effects of social media use by patients for health-related reasons. This review included papers that satisfied seven inclusion criteria. Out of 1,743 abstracts initially identified, twenty-two papers met our inclusion criteria and were included in the review. We identified five types of social media use by patients, namely emotional, informational, esteem, network support, and social comparison. We linked these types of use to the effects on patients and their relationship with healthcare providers. Our review provides systematic insight into the emerging role of social media in healthcare and serves as a guide for future research. In particular, our findings point to a lack of attention to the role of social media in the changing relationship between patients and healthcare professionals and a need to further study this topic.

[1] This chapter was written together with Albert Boonstra, David Langley and Wyanda Hooijsma. It was published in *BMC Health Services Research* (2016).

2.1 Introduction

Extant literature on social media in healthcare identified some effects of social media use by patients. In particular, social media allow patients to complement the information received from healthcare professionals, receive support and become empowered (Hawn, 2009; Ho et al., 2014; Rupert et al., 2014). Social media use by patients can also facilitate the work of healthcare professionals by strengthening the market position of healthcare professionals and improving delivery of their services (McCaughey et al., 2014). However, this use by patients may also represent a challenge to patients and healthcare professionals. Healthcare professionals worry that social media use by patients could spread misinformation (Rupert et al., 2014). For example, patients may provide wrong advice that leads to worsening of the health condition of those who follow it (Carter, 2014).

Therefore, it is important to systematically review these different effects as patients are increasingly using social media to exchange health information (Antheunis et al., 2013). Such review can advance our understanding of the benefits and challenges with regards to patients and healthcare professionals. In this chapter, we provide a systematic literature review of empirical papers on the effects on patients stemming from their use of social media and also how this influences their relationship with healthcare professionals. The review can serve as a good overview of the extant literature and future research avenues. It can also help health professionals to adjust their health services accordingly. Moreover, it can help policymakers to understand better the current effects of social media in healthcare, which could serve to better design health policies in this context. The next section describes our aim and states research question for this chapter.

2.1.1 Chapter aim and terminology

This review aims to provide a better understanding of the social media use by patients and its related effects. In particular, it focuses on the effects on patients and their relationship with healthcare professionals. In line with this aim, we address the following research question:

What are the effects on patients from their use of social media and how does this influence their relationship with healthcare professionals as reported in extant literature?

In this chapter, we use the term social media to include a group of Internet-based applications that allow the creation, modification, and exchange of user-generated content (Kaplan & Haenlein, 2010). By patients, we refer to users of social media for health-related purposes. Healthcare professionals refer to different professionals who provide preventive or curative health services to diagnose and treat health issues.

2.2 Methods

We aimed to provide a comprehensive overview of social media use by patients and identify the related effects. In line with this, we conducted the systematic literature review. Following the review, we analyzed our data following the aim of our review.

2.2.1 Review selection criteria

Before the review, we defined criteria to include or exclude papers from the review. In particular, we only included papers that were empirical, in English, published in peer-reviewed journals, focused on social media use for health-related purposes by patients, and where the effects of social media were clearly identifiable. We also conducted a quality assessment using the established framework (Kmet, Lee, & Cook, 2004). This quality assessment had two checklists, one for qualitative and one for quantitative papers.

Before final screening and selection of the papers, the first (ES) and second author (WH) independently read 100 abstracts and selected the articles to be included in the review based on the previously mentioned selection criteria. For some of the articles, the first and second author

had a discussion to reach a consensus. This helped to reach higher reliability for the inclusion of the articles.

2.2.2 Search strategy

We conducted our search in the Web of Science and EBSCOhost Complete. We included relevant healthcare databases such as “PsycINFO”, “CINAHL” and “MEDLINE”. We also included more extensive databases such as “Business Source Premier”. Search options were slightly different for the Web of Science and EBSCOhost Complete. In EBSCOhost Complete, no specific search field was selected for one of the three categories. In the Web of Science, we selected the field topic. This particular field covered the search in the titles, abstracts, author keywords, and keywords. In addition, we focused on the period starting from 2004, which is seen as the year in which social media started (Kaplan & Haenlein, 2010). The complete list of included databases is listed in Appendix A.

We used the search strategy comprising of three categories, namely 1) “social media” or blog* or “content communit*” or “social networking site*” or “online social network*” or “virtual world*” or “online communit*” or “online forum*” or Facebook or Twitter or Wikipedia or IMVU or “second life” or YouTube 2) “Patient*” or and 3) “health* provider*” or “health* professional*” or “physician*” or “doctor*” or “hospital*”. In addition, based on the suggestion of the reviewers for a publication, which resulted from this chapter, we included an additional category of “client*” under 2.

2.2.3 Data analysis

The resulting papers were characterized by the research aim and the type of research, which is reflected in table 2.1. The papers were further categorized according to the focus of the research question and data. Each paper’s empirical findings were categorized by looking at the data and making the first notes inductively. Following this, we looked at our notes on topics that emerged from analyzed articles and compared them to earlier literature. In this way, concepts from prior

literature helped us to make sense of the data from different articles and to categorize them. For example, we used concepts of informational and emotional support, to classify types of use.

2.3 Results

2.3.1 Included articles

Our initial search resulted in a total of 1,743 articles. After an initial check of the abstracts, we excluded 468 duplicate articles. We identified these both within databases as well as between different databases. We then analyzed the remaining titles and abstracts. In some cases, we were not sure if the article should be included or not. In such cases, we accessed and read the full article. We also excluded articles based on our selection criteria. An article was removed when, for example, it was clear that the users of social media were not patients, but actually healthcare professionals. In addition, some articles discussed the use of Internet resources by patients, but not specifically social media. In the end, we had 22 articles that met our selection criteria. In addition, as a result of the reviewer's suggestion to include term "client", we identified one additional article, making the entire list of 23 articles for the quality assessment. As noted in the methods section, we used the established framework to evaluate the quality of papers (Kmet et al., 2004). Based on this quality check, we excluded one article, which left us with 22 for final analysis. The article selection process is shown in figure 2.1. Table 2.1 presents an overview of 22 articles included in the review.

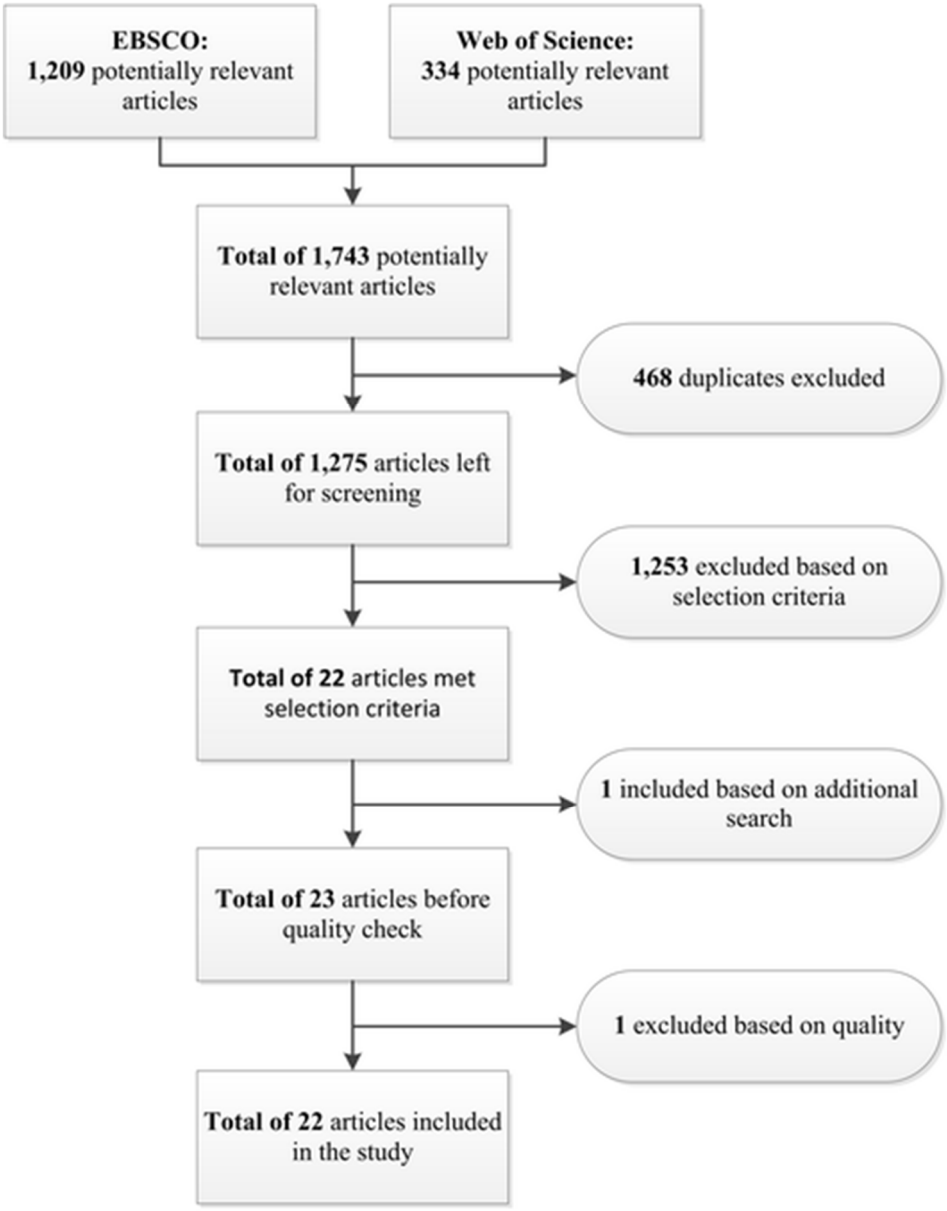

Figure 2.1 Selection process

Table 2.1 Overview of included articles

Article No.	Year	Author(s) - Article no.	Journal	Main aim of study	Type of research	Data collection
1	2005	(Broom, 2005a)	Journal of Sociology	To explore the experiences of, and attitudes towards, online support groups.	Qualitative	Interviews
2	2008	(van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008)	Journal of Medical Internet Research	To explore whether lurkers in online patient support groups profit to the same extent as posters do.	Quantitative	Online survey
3	2008	(Frost & Massagli, 2008)	Journal of Medical Internet Research	To identify and analyze how users of the platform PatientsLikeMe reference personal health information within patient-to-patient dialogues.	Qualitative	Analysis of comments
4	2010	(Colineau & Paris, 2010)	New Review of Hypermedia & Multimedia	To understand why and how people use health-related sites.	Quantitative	Online survey
5	2010	(Bers et al., 2010)	Pedriatic Transplantation	To investigate the feasibility and safety of an online virtual community as a potential psychosocial intervention for post-transplant adolescents.	Qualitative and Quantitative	Data analysis of the Zora system logs and interviews
6	2010	(Malik & Coulson, 2010)	Journal of Psychosomatic Obstetrics & Gynecology	To focus on investigating the perceived disadvantages of online infertility support communities from the perspective of those who access and participate in them.	Qualitative and Quantitative	Online survey
7	2010	(Wicks et al., 2010)	Journal of Medical Internet Research	To describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes.	Quantitative	Online survey
8	2011	(Bartlett & Coulson, 2011)	Patient Education and Counseling	To investigate the potential of online support groups to foster empowerment and how membership might affect the patient/health professional relationship.	Quantitative	Online survey
9	2011	(Setoyama, Yamazaki, & Namayama, 2011)	Journal of Medical Internet Research	To explore the differences in peer support received by lurkers and posters in online breast cancer communities.	Quantitative	Online survey
10	2012	(Gómez-Zúñiga, 2012)	Medicine 2.0	To explore the motivations and challenges faced by patients who share videos about their health and experiences on YouTube.	Qualitative	Analysis of videos

11	2012	(Oh & Lee, 2012)	Health Communication	To examine the indirect effect of Computer-Mediated Social Support on doctor-patient communication through utilizing the sense of empowerment.	Quantitative	Online survey
12	2012	(Kim & Yoon, 2012)	Information Research	To examine the use of an online health forum by married Korean women living in the USA who sought help for health and medical issues.	Qualitative	Content analysis of posts
13	2013	(Wentzer & Bygholm, 2013)	International Journal of Medical Informatics	To investigate whether communication in online patient support groups is a source of the individual as well as collective empowerment or to be understood within the tradition of compliance.	Qualitative	Analysis of posts
14	2013	(Chiu & Hsieh, 2013)	Journal of Health Psychology	To explore how cancer patients' writing and reading on the Internet play a role in their conditions experience.	Qualitative	Focus-group interviews
15	2013	(Coulson, 2013)	JRSM short reports	To explore how participation in an online support community may impact upon the experience of inflammatory bowel disease.	Qualitative and Quantitative	Online survey
16	2013	(Bauer, Bauer, Spiessl, & Kagerbauer, 2013)	Nordic Journal of Psychiatry	To evaluate if and how online self-help forums are used by patients with bipolar disorders, their relatives and treating professionals.	Qualitative and Quantitative	Content analysis of posts
17	2014	(Rupert et al., 2014)	Patient Education & Counseling	To explore how individuals use online health community content in clinical discussions and how healthcare providers react to it.	Qualitative	Focus groups
18	2014	(Kofinas et al., 2014)	Obstetrics & Gynecology	To determine whether social media, specifically Facebook, is an effective tool for improving contraceptive knowledge.	Quantitative	Survey
19	2014	(Menon, Sharma, Chandra, & Thennarasu, 2014)	Indian Journal of Psychological Medicine	To explore the potentials of social networking sites as an adjunctive treatment modality for initiating treatment contact as well as for managing psychological problems.	Qualitative and Quantitative	Interviews and an online survey
20	2014	(Lee & Wu, 2014)	Reproductive Health	To use the online platform of blogs to explore whether the framing effect of information content, situated learning of information content, and health knowledge involvement would affect health communication between doctors and patients and further explore whether this would increase patient willingness to seek treatment.	Quantitative	Online survey
21	2014	(Pagoto et al., 2014)	Journal of the American Medical	To describe adults who use Twitter during a weight loss attempt and to compare the positive and negative social influences they experience from their offline friends, online friends, and family members.	Qualitative and Quantitative	Survey

			Informatics Association			
22	2016	(Farber & Nitzburg, 2015)	Counselling Psychology Quarterly	To test for differences between offline and online psychological disclosure in case of young adults.	Quantitative	Survey

2.3.2 Types of social media use by patients

We identified that one of the primary reasons to use social media for health-related purposes by patients was the fact that some of their emotional needs are not adequately met in traditional offline interaction with healthcare professionals (Rupert et al., 2014). In line with that, another motivation for patients was to collect additional information about their condition (Gómez-Zúñiga, 2012). Hence, they regard social media as an important addition to traditional offline interactions to learn more about their condition (Kofinas et al., 2014).

These initial motivations guided our analysis of social media use by patients. In particular, we focused on the use that facilitated filling their unmet needs. We identified five categories of use, namely emotional support, informational support, esteem support, network support, and social comparison. In identifying these categories of use, the concepts from prior literature such as informational and emotional support helped us to categorize our findings. Table 2.2 provides an overview of the use per identified articles.

Table 2.2 Types of social media use by patients

Type of use	Articles
Emotional support	(Bartlett & Coulson, 2011; Bauer et al., 2013; Broom, 2005a; Chiu & Hsieh, 2013; Colineau & Paris, 2010; Coulson, 2013; Farber & Nitzburg, 2015; Gómez-Zúñiga, 2012; Kim & Yoon, 2012; Malik & Coulson, 2010; Menon et al., 2014; Oh, Lee, 2012; Rupert et al., 2014; Setoyama et al., 2011; van Uden-Kraan et al., 2008; Wentzer & Bygholm, 2013; Wicks et al., 2010)
Informational support	(Bartlett & Coulson, 2011; Bauer et al., 2013; Bers et al., 2010; Broom, 2005a; Chiu & Hsieh, 2013; Colineau & Paris, 2010; Coulson, 2013; Farber & Nitzburg, 2015; Frost & Massagli, 2008; Gómez-Zúñiga, 2012; Kim & Yoon, 2012; Kofinas et al., 2014; Lee & Wu, 2014; Malik & Coulson, 2010; Menon et al., 2014; Oh, Lee, 2012; Pagoto et al., 2014; Rupert et al., 2014; Setoyama et al., 2011; van Uden-Kraan et al., 2008; Wentzer & Bygholm, 2013; Wicks et al., 2010)
Esteem support	(Bartlett & Coulson, 2011; Chiu & Hsieh, 2013; Coulson, 2013; Gómez-Zúñiga, 2012; Oh, Lee, 2012; Pagoto et al., 2014; Wentzer & Bygholm, 2013)
Network support	(Bauer et al., 2013; Bers et al., 2010; Chiu & Hsieh, 2013; Colineau & Paris, 2010; Coulson, 2013; Frost & Massagli, 2008; Gómez-Zúñiga, 2012; Menon et al., 2014; Pagoto et al., 2014; Rupert et al., 2014; Setoyama et al., 2011; Wentzer & Bygholm, 2013; Wicks et al., 2010)
Social comparison	(Bartlett & Coulson, 2011; Coulson, 2013; Malik & Coulson, 2010; Pagoto et al., 2014)

Emotional support

Emotional support was one of the most common types of use by patients in the articles we identified. We define this use as intended to meet emotional needs. For example, it includes sharing emotions with other patients and receiving support in handling emotional difficulties associated with their health condition (Bartlett & Coulson, 2011; Menon et al., 2014). It is seen as directed to sharing care and concern for themselves and others (Colineau & Paris, 2010). We identified this type of use in 17 articles. Examples we identified ranged from sharing emotional experiences about their health condition to talking about the feelings of other patients (Colineau & Paris, 2010; Coulson, 2013; Setoyama et al., 2011).

Informational support

This is the most common type of use, which we identified in all articles. We define this type of use as the communication that provides useful information about health conditions. This type of communication mostly takes place between newly diagnosed patients who are in search of information and experiences of others (Chiu & Hsieh, 2013). Such use was often about exchanging advice around dealing with conditions and sharing relevant personal experiences about symptoms (Chiu & Hsieh, 2013; Setoyama et al., 2011). This type of use entailed sharing their own experiences of dealing with the condition and also asking other patients how to deal with certain aspects of their condition (Coulson, 2013).

Esteem support

We define esteem support as a type of use that is aimed at one's beliefs in being able to deal with a condition or take action. Through this type of use, patients encourage each other to take actions that will help them with their situation. As such, it was identified in seven articles. For example, this covers discussion over questions on how to use social media to provide and receive encouragement before patients go for treatments (Chiu & Hsieh, 2013). Another

example includes receiving reassurance from other patients to follow specific courses of action (Wentzer & Bygholm, 2013).

Network support

Concerning this chapter, we define network support as a type of use, which provides the sense of belonging to a network. We identified this type of use by patients in 13 articles. The examples of a patient's use of social media for this purpose include the use that was directed at meeting others in order to be part of the patient network (Bers et al., 2010). Furthermore, this use is really about connecting with others who are in the same or similar situation (Frost & Massagli, 2008).

Social comparison

Whereas other types of use we identified were closely related to the concept of social support, we found that this type of use by patients was directed towards comparing their situation with others. In particular, this use entailed comparing how good or bad their situation was in relation to other patients who were using the same social media (Bartlett & Coulson, 2011). This type of use is somewhat close to other identified types of use, which predominantly focused on receiving or providing support. Yet, we categorized this type of use as distinct as the articles did not specify details if such comparison was for the reason of support or not. We found this type of use to be described in four of the reviewed articles.

2.3.3 Effects of social media use on patients

We identified enhanced positive effects for patients such as improved well-being and self-management of the disease, but also some not so positive effects of using social media such as reduced well-being, lost privacy, and addiction to social media. The categories of enhanced well-being and better self-management are closely related to the concept of patient empowerment. We come back to this issue in discussing our results. Whereas these effects were

common in the articles we reviewed, the effects such as lost privacy and addiction to social media were identified only in few of the articles. Table 2.3 provides an overview of the effects on patients identified in our review.

Table 2.3 Effects of social media use on patients

Effects on patients	**Articles**
Improved well being	(Bartlett & Coulson, 2011; Bauer et al., 2013; Bers et al., 2010; Broom, 2005a; Chiu & Hsieh, 2013; Colineau & Paris, 2010; Coulson, 2013; Farber & Nitzburg, 2015; Frost & Massagli, 2008; Gómez-Zúñiga, 2012; Menon et al., 2014; Oh, Lee, 2012; Pagoto et al., 2014; Setoyama et al., 2011; van Uden-Kraan et al., 2008; Wentzer & Bygholm, 2013; Wicks et al., 2010)
Improved self-management	(Bartlett & Coulson, 2011; Bauer et al., 2013; Chiu & Hsieh, 2013; Colineau & Paris, 2010; Coulson, 2013; Frost & Massagli, 2008; Gómez-Zúñiga, 2012; Kim & Yoon, 2012; Kofinas et al., 2014; Lee & Wu, 2014; Oh, Lee, 2012; Setoyama et al., 2011; van Uden-Kraan et al., 2008; Wentzer & Bygholm, 2013; Wicks et al., 2010)
Reduced well being	(Broom, 2005a; Coulson, 2013; Gómez-Zúñiga, 2012; Malik & Coulson, 2010; Setoyama et al., 2011; Wicks et al., 2010)
Lost privacy	(Gómez-Zúñiga, 2012)
Addiction to social media	(Malik & Coulson, 2010)

Improved well-being

We define well-being as positive thoughts and feelings about oneself to fulfill a meaningful life (Bauer et al., 2013; Farber & Nitzburg, 2015). In line with this overarching definition, we relate it to the effects that are related to good emotions and positive experiences that patients experienced after using social media. We identified this effect in 17 articles. One of the results related to such effects is achieving positive relations with others through communication, which took place on social media. This is in line with the argument that well-being is enhanced with an increase in good emotions. For example, the patients who were using social media for health-related purposes were more able to accept and deal with their disease (Bartlett & Coulson, 2011). Furthermore, the use of social media by patients helped them to be less anxious and to feel more optimistic (Setoyama et al., 2011; van Uden-Kraan et al., 2008). Another example shows that the use of social media helped patients to connect, but also to build deep relations

with other patients through social media, which led to feeling good (Bauer et al., 2013; Colineau & Paris, 2010).

Improved self-management

The effect of improved self-management is associated with improvements in managing health conditions. In this respect, the role of social media was to provide the patients with the right information, which improves self-management of the condition and the perception of control over their condition (Bauer et al., 2013). This effect of social media use through learning from other patients online facilitated daily coping with the condition (Wicks et al., 2010). We identified these effects in 15 articles. Examples of such effects show increased self-management of the condition, improvements in the condition, and perceived feelings of greater control over the condition (Bauer et al., 2013; Gómez-Zúñiga, 2012; Setoyama et al., 2011).

Reduced well-being

In essence, reduced well-being is the opposite of improved well-being. Hence, it entails an increase in negative emotions due to the use of social media. An example of this includes experiencing feelings of anxiety (Coulson, 2013). We identified these effects on patients in six articles. Further examples of such effects have shown that patients sometimes felt demoralized and negative about their situation due to the use of social media (Gómez-Zúñiga, 2012).

Loss of privacy

This particular effect was explicitly related to the use of YouTube. Those patients who posted their videos on YouTube felt particular positive outcomes, however, at the same time, they also felt that they lost their privacy (Gómez-Zúñiga, 2012).

Addiction to social media

This type of effect on patients was also identified in a single article. The patients who described this effect felt that they were getting addicted to the use of social media for health-related

purposes. In particular, they felt a need to use social media frequently, which took time from doing other things (Malik & Coulson, 2010).

2.3.4 Effects of social media use on the patient-healthcare professional relationship

In total, we identified nine articles that discussed the effects of social media use by patients on their relationship with healthcare professionals. We describe each of the effects below and provide an overview in table 2.4.

Table 2.4 Effects of social media on the patient-healthcare professional relationship

Effects on patients	Articles
More equal relationship	(Bartlett & Coulson, 2011; Lee & Wu, 2014; Oh & Lee, 2012; van Uden-Kraan et al., 2008; Wicks et al., 2010)
Increased switching of doctors	(Rupert et al., 2014; Wicks et al., 2010)
Harmonious relationship	(Chiu & Hsieh, 2013; Wentzer & Bygholm, 2013)
Degraded relationship	(Broom, 2005a; Rupert et al., 2014)

More equal relationship

In five of the articles, we identified that the use of social media by patients improved their relationship with their healthcare professionals, with patients reporting that social media made them feel less inferior to their providers. By this, we mean that the patient became more confident in this patient-provider relationship. We identified this particular effect in five of the articles. With the information sourced from social media, the patients increase their knowledge about their condition and the available treatments (Bartlett & Coulson, 2011; Pagoto et al., 2014). As a result, patients understand their condition better and are more able to speak about it with their doctor (Wicks et al., 2010) and also showed increased confidence (Bartlett & Coulson, 2011). Being more informed also helped patients to ask more relevant questions. Overall, the use of social media, in particular for informational support, increased the level of active communication with the healthcare professionals (Oh & Lee, 2012). The increased attention of patients ultimately led to more interactions with the healthcare professionals (Lee

& Wu, 2014). Overall, these results indicate that the use of social media by patients boosts their confidence and improves their communication with healthcare professionals.

Increased switching of doctors

Social media use by patients for health-related reasons also lead to increased switching of doctors. We identified such effect in two articles. In these articles, the patients decided to switch their current doctors due to the use of social media for two reasons. Firstly, they changed their doctor when they informed doctors about the use of social media and these doctors were critical of such use (Rupert et al., 2014). Secondly, the patients engaged into social media discussions and found that other doctors may be better suited to their needs as a result of the information obtained on social media (Wicks et al., 2010).

Harmonious relationship

Harmonious relationships between healthcare professionals and patients can be established as social media help patients to release their negative thoughts and emotions, thus receiving emotional support. In addition, patients can obtain information on social media, which will facilitate following the advice from their healthcare professional. We identified this effect in two articles. For example, social media use by patients facilitated getting the emotional support online from their fellow patients, which then led to better focus on other aspects in their interactions with healthcare professionals (Chiu & Hsieh, 2013). In another example of this effect on the patient-healthcare professional relationship, the information obtained from social media empowered compliance with the advice of their healthcare professionals (Wentzer & Bygholm, 2013). Hence, they felt that the relationship with their healthcare professional was good and harmonious.

Degraded relationship

While the relationship with healthcare professionals could be improved as the result of social media use by patients, it can also be degraded. In particular, such situation could occur if patients find the information from social media more credible than the information from their healthcare professionals (Agarwal et al., 2010). We found evidence of this in two of the reviewed articles. Specifically, one degraded relationship occurred when a patient challenged the healthcare professional with information he found on social media (Broom, 2005a). The healthcare professional felt that his medical expertise was being challenged by laymen, leading to a strained relationship. In another article, a degraded relationship with healthcare professional was the result of negative reactions of the healthcare professionals to the information patients found on social media (Rupert et al., 2014). This made the patients feel dishonored, and it affected their relationship with healthcare professionals.

2.4 Discussion

This review provides an insight into the extant literature on the use of social media by patients and the effects of such use on patients and their relationship with healthcare professionals. Most of the reviewed articles were published in the last few years, which indicates an increasing interest and a need to study this topic.

We categorized articles into different types of use and effects. We identified that the most common types of use were emotional support and informational support. In regards to the types of effects on patients, we found that it affected their well-being and self-management. The effects of improved well-being and self-management are closely related to the concept of patient empowerment, which is seen as increased control of one's disease and having the necessary knowledge and skills to do so (Bartlett & Coulson, 2011).

However, the effects of social media use were not all positive, reduced well-being, lost privacy, and addiction to social media were also noted. We also found limited evidence on the effects of social media use and the effects on their relationship with healthcare professionals. These effects included having a more equal relationship, an increased switching of doctors, more harmonious relationships, and more degraded relationships between patients and healthcare professionals. Based on our results, we develop three propositions.

2.4.1 Relationship between network support and improved well-being and the role of self-esteem

As a result of the condition they are diagnosed with, the patients can feel lonely and isolated (Gómez-Zúñiga, 2012). This is especially the case when nobody in their circle of friends and colleagues has such condition (Bers et al., 2010). In such cases, social media facilitate patients in finding fellow patients to be part of the network and to have a sense of belonging to that network (Setoyama et al., 2011). When they feel part of the network and receive network support on social media, they can feel less lonely (Colineau & Paris, 2010). Extant literature on offline network support highlighted the benefits of improved well-being for the families of patients (Magliano et al., 2001). Hence, the use of social media by patients for the reason of network support may lead to improved well-being. However, the extent to which the network support affects well-being depends on how patients feel about it. Specifically, the concept of self-esteem may play a role in this relationship. Individuals with low self-esteem may experience more challenges in talking to others and sharing their experiences in traditional offline interactions (Broom, 2005a). Such challenges could limit network support that the patients with low self-esteem can build offline. However, the possibility to build network support through social media increase their likelihood to talk and share with others (Steinfield, Ellison, & Lampe, 2008). Thus, we propose that the relationship between network support and

improved well-being will be more pronounced for the patients with low self-esteem than for the patients with high self-esteem.

Proposition 1: Self-esteem will moderate the effect of network support obtained from social media and improved well-being. Specifically, this effect will be more pronounced for the patients with low self-esteem than for the patients with high self-esteem.

2.4.2 The role of being lurker vs. being a contributor in the effects of social media use on the well-being

Users of social media, in general, can be either so-called "lurkers" or "contributors". While lurkers mostly read and use what others post, contributors actively participate in and contribute to discussions (Phang, Kankanhalli, & Tan, 2015). The same pattern of behavior applies to online behavior in the context of healthcare (van Uden-Kraan et al., 2008). We identified only two articles that clearly linked lurking behavior to the use of social media for informational support (Setoyama et al., 2011; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009). In these cases, reading about experiences of others without actively contributing to the discussions represented informational support. Furthermore, this also led to reduced levels of anxiety (Setoyama et al., 2011). Thus, on the one hand, this suggests that lurking behavior by patients in their social media use may lead to improved well-being. However, on the other hand, we found that the patients who read negative stories experienced reduced well-being (Coulson, 2013; Malik & Coulson, 2010). Interestingly, we also identified an article in which content about negative experiences led to improved well-being (Chiu & Hsieh, 2013). This particular article focused on blogs where the patients acted as contributors. By being able to contribute and share their experiences, the users can express their thoughts and feelings (Kaplan & Haenlein, 2010). Such contributing role helps patients to vent their negative feelings on social media. Thus, we propose that reading about negative experiences will lead to reduced well-

being for lurkers, whereas writing about negative experiences will lead to improved well-being for contributors.

Proposition 2: Reading about negative experiences of others will lead to reduced well-being for lurkers and writing about negative experiences will lead to improved well-being for contributors.

2.4.3 Relationship between patients and healthcare professionals: a shift in power balance and increased quality of decision making

The effects of social media use by patients for health-related reasons show that social media use by patients can lead to improved well-being and self-management, which are related to patient empowerment. Patient empowerment is an established concept in medical research and has been promoted to foster patient autonomy (Feste & Anderson, 1995). As a result of patient empowerment, patients may increasingly interact with their healthcare professional and get more involved in the decision making process (Colineau & Paris, 2010). In this case, social media can be seen as a "new" technology adopted by patients, which may shift the power balance between the healthcare professional and the patient. In this line, patients can participate in their interactions with healthcare professionals actively. However, this could make the healthcare professionals feel challenged in regards to their expertise and power (Rupert et al., 2014). Yet, the role of health professionals has to change because embracing patient empowerment in healthcare means making a change (Feste & Anderson, 1995).

However, increased patient involvement in the clinical interaction could potentially increase the risk placed on healthcare professionals (Broom, 2005a). Healthcare professional may not be in complete control of the information used during decision-making, but the healthcare professional bears full responsibility for the decisions taken. When patients bring in information elicited from social media to their consultations, this could lead to unnecessary processes of

sorting relevant information from irrelevant information and can be experienced as challenging the healthcare professional's expertise (Rupert et al., 2014). Hence, based on these findings it is possible for healthcare professionals to resist this shift in the balance of power. However, the more equal relationship between patients and healthcare professionals may also lead to positive effects, making healthcare professionals more patient-centered, thus complementing patient empowerment (Holmström & Röing, 2010). As a consequence of patient empowerment, we propose that the quality of clinical decision-making may be enhanced. This could provide an opportunity to increase the quality of the treatment decisions.

Proposition 3: As a result of patient empowerment due to patients using social media for health-related reasons, the power balance between healthcare professionals and patients becomes more equalized, leading to increased quality of clinical decisions making.

2.5 Conclusion

The use of social media by patients for health-related reasons is increasing. This systematic literature review provides some insights on extant literature related to social media use by patients and the effects of such use. Results of our review show that the patients use social media mostly for informational and emotional support. Less present types of use were in particular social comparison. In regards to the effects, most of the identified effects were related to the concept of patient empowerment, notably improved well-being, and improved self-management. We also discovered effects such as lost privacy and addiction to social media. Relating to the effects of social media use by patients on the relationship with healthcare professionals, we found limited evidence. However, we were able to identify effects such as more equal relationships, increased switching of doctors, more harmonious relationships and more degraded relationships. Whereas this evidence is limited, we explicitly encourage future research in this direction.

Notwithstanding the interesting results described above, this research has some limitations, which, along with the three propositions, suggest opportunities for further research. It is possible that we missed some articles that could have used different terminology. Consequently, the results of this chapter might not be generalizable for all social media platforms. For practical reasons, we excluded non-English papers. Finally, a limitation of every literature review is that the authors of the included articles will have had different objectives and used different methods and means of interpretation in reaching their conclusions. In this chapter, we highlighted the most important findings on our topic, and we categorized the key effects of social media use on patients and their relationships with healthcare professionals.

Chapter 3. Taxonomy of social media enabled interactions in healthcare[2]

Abstract

Healthcare users and providers have increasingly been utilizing social media to communicate with one another. It is suggested that this online communication may also affect their offline interactions. It is essential to develop a solid understanding of social media enabled interactions as a first step in exploring the effects of these interactions on their offline interaction. Extant research focuses on two broad types of social media use in healthcare, namely informational and emotional support. However, we still lack a deeper understanding of who interacts, about what and how these interactions can be categorized into a taxonomy. Taxonomies are used to develop classifications and categories in such a way that the potential effects of phenomena can better be identified and analyzed. Thus, the development of taxonomy is essential to further explore potential effects of social media enabled interactions on offline interactions between healthcare providers and users. In this chapter, we employ a mixed method approach to a sample of cases from contrasting categories of social media, and we study interactions among healthcare users and providers. We identify five archetypical interactions and categorize them into a taxonomy. We show that the dominant categorization of health-related social media use in the literature, namely informational and emotional support, is inadequate.

[2] This chapter was written together with Albert Boonstra and David Langley. Earlier version of this chapter was presented at European Conference on Information Systems (2015).

3.1 Introduction

The focus of this chapter is to provide a taxonomy of social media enabled interactions in healthcare to facilitate a better understanding of online interactions as well as their potential effects on offline communication between healthcare users and providers. The rise of social media in healthcare enabled healthcare users to move from one-to-one to one-to-many and many-to-many communication (Hawn, 2009). In line with this, the healthcare users' utilization of social media has gained in importance and prevalence (Zhao et al., 2013; Ziebland & Wyke, 2012). Such use enables them to access health-related information, interpret the information, and contribute their own experiences, bringing benefit to them and to others (Adams, 2010). Resultantly, healthcare users are able to find the information they require and feel supported (Ziebland & Wyke, 2012), increase their knowledge and exchange advice with others (Antheunis et al., 2013), feel empowered in the sense that their meaning, competence, and self-determination to manage their own health increases (Johnston, Worrell, Di Gangi, & Wasko, 2013), and make better informed decisions (Wicks et al., 2010). However, extant research has thus far provided merely an overview of social media in healthcare (Antheunis et al., 2013; Chou, Prestin, Lyons, & Wen, 2013; Ziebland & Wyke, 2012). Hence, we still know little about social media with a focus on health (Faraj, von Krogh, Monteiro, & Lakhani, 2016).

This limited understanding of social media enabled interactions makes it difficult to predict or have a clear understanding of how social media may affect offline interactions of healthcare users with their providers. On the one hand, using social media to augment traditional access to information may help improve the healthcare user ability to self-manage their condition (Bauer et al., 2013; Merolli et al., 2015). Hence, it could be seen as a learning health system and potentially improve interactions between healthcare users and healthcare providers (Friedman et al., 2010). On the other hand, given the high proliferation of social media in healthcare (Kane

et al., 2009), information systems (IS) researchers propose that social media may challenge the relationship between healthcare users and healthcare providers (Agarwal et al., 2010).

The first step towards understanding potential effects of social media in healthcare and, in particular, on the relationship between healthcare users and their healthcare providers is to understand how healthcare users are using social media for health-related purposes (Agarwal et al., 2010). Extant research focuses on two broad types of social media use in healthcare, namely informational and emotional support (Wang, Kraut, & Levine, 2015). Moreover, studies mostly focus on a single social media category such as social networking sites (Khang, Ki, & Ye, 2012). Hence, it remains ambiguous *who* interacts with *whom, about what,* and *which types* of interactions take place within the different categories of social media. Furthermore, these interactions are not categorized into taxonomy whereas taxonomy can facilitate increased clarity of potential diverse effects and their causes (Fiss, 2011; Sofaer, 1999).

Thus, this chapter aims to develop a taxonomy of social media enabled interactions in healthcare. Hence, we focus on the following research question:

What are the typical interactions in health-related social media and how can we categorize them in taxonomy?

To address our research question, we follow a mixed methods approach, integrating qualitative and quantitative methods to analyze a purposive sample of interactions from contrasting types of social media platforms, and to develop our taxonomy.

We aim to contribute to the literature streams on health information systems and social media. In this respect, we make several contributions to the current literature. Firstly, we add to the health information technology literature (HIT), which has traditionally focused on topics such as privacy concerns, interoperability, and resistance to change (Romanow, Cho, & Straub, 2012). To do this, we analyze how healthcare users are using social media and thus answer

recent calls for research into this matter (Agarwal et al., 2010; Fichman et al., 2011). Moreover, we propose a taxonomy of social media interactions in healthcare that has not been published to date. Taxonomies are organized systems of types and represent important forms that aid in the understanding of complex causal-effect relationships (Fiss, 2011). Thus, the taxonomy enables further systematic exploration of challenges and benefits that social media bring to the healthcare domain, and it complements literature in other industries (Aral et al., 2013; Dong & Wu, 2015; Jarvenpaa & Tuunainen, 2013). Secondly, we contribute to the literature stream on social media by addressing how social media features are utilized by users, which has been identified as an important topic for future research (Aral et al., 2013). We do so by deepening the concepts of informational and emotional support and discovering a new distinct type of use, namely lifestyle support. We base our findings on different categories of social media and their differences, whereas earlier research has mostly focused on the single category of social media.

Practically, we provide an improved understanding of the role that social media plays for actors in the healthcare domain. Healthcare providers and policymakers are uncertain about the way in which social media is changing healthcare provision and how they should respond to this increasing utilization by healthcare users (Agarwal et al., 2010; Fichman et al., 2011). Additionally, managers of social media platforms can learn more about the way in which their platforms are being used, how they can improve their designs and how social media may provide a base for a possible shift in healthcare provision.

The first section of this chapter will provide an overview of the current literature on social media, specifically in the healthcare context and rationale for our choice of taxonomy dimensions. Following that, we describe our research setting and the different methods we

employed. We then proceed with our empirical results, and we present our taxonomy. We conclude with a discussion of our findings in light of the extant literature.

3.2 Theoretical Background

3.2.1 Social media

Social media represent emerging technologies with the potential to allow for flexible, adaptable, and easy sharing of online knowledge. Social media technologies have been previously used in healthcare, yet very little research has been conducted categorizing online interactions. Web 2.0 as the main enabler of social media was first used in 2004 to define a new way for software designers and end users to use the World Wide Web (Kaplan & Haenlein, 2010). Web 2.0 enables the creation of content that can be modified by everyone in a participatory fashion. On these grounds, social media changed the role of online users making it much more active regarding their ability to communicate and add user-generated content (Bishop, 2007). The change facilitated new interactions between the participants that were not possible in the past. This participatory aspect of bringing users together in a way that enables them to access and change content forms the foundation of social media. Social media are the Internet-based applications built on Web 2.0 that enable making and exchanging user-generated content (Kaplan & Haenlein, 2010). In this way, Kaplan and Haenlein (2010) make the distinction between social media and Web 2.0. While Web 2.0 serves as the foundation, social media represents user-generated content as the result of Web 2.0 use. Accordingly, we can define social media as the platforms based on Web 2.0 technological foundations that make it possible for users to create, discuss, and modify the content. The difference between these technologies and other standard forms of information and communication technologies is that social media allow users to make their views, perceptions, and knowledge public.

3.2.2 Social media taxonomies

For the time being, there is only one taxonomy of different social media categories, proposed by Kaplan and Haenlein (2010), it is based on the two dimensions social presence/media richness and self-presentation/disclosure. Social presence refers to the type of contact that can be achieved and media richness indicates the amount of information that can be shared and function of the characteristics such as ability to facilitate rapid feedback and ability to handle multiple information cues simultaneously. On the other hand, self-presentation/disclosure refers to the revelation of personal information to impress others. Along these lines, Kaplan and Haenlein (2010) divide social media applications into six categories as shown in figure 3.1.

		Social presence/Media richness		
		Low	**Medium**	**High**
Self-presentation/ Self-disclosure	**High**	Blogs	Social networking sites (e.g., Facebook)	Virtual social worlds (e.g., Second Life)
	Low	Collaborative projects (e.g., Wikipedia)	Content communities (e.g., YouTube)	Virtual game worlds (e.g., World of Warcraft)

Figure 3.1 Social Media Taxonomy (Kaplan & Haenlein, 2010)

Based on the aspects of media richness and self-presentation, Kaplan and Haenlein (2010) divided social media into six different categories: collaborative projects, blogs, content communities, social networking sites, virtual game worlds, and virtual social worlds. Collaborative projects constitute platforms where many users can jointly create and modify content simultaneously and are often referred to as wikis. Blogs are websites where one user posts his/her content, usually in chronological order, and other users may comment but are unable to change the original posts. Content communities are repositories of many types of content, including the well-known YouTube, which enables the sharing of media content between users. Social networking sites are applications that enable users to create personal

profiles that their friends can access and utilize to interact with them. Virtual worlds are simulated 3D environments in which users can choose their avatars and use them to interact with other users. There are two types of virtual worlds (1) virtual game worlds where users are required to abide by the rules of the game they are playing, and (2) virtual social worlds where users can behave as they choose.

3.2.3 Social media in healthcare

A growing body of literature recognizes the importance of social media in healthcare. This research indicates that social media are used by healthcare providers (Van de Belt et al., 2012) and healthcare users (Greene, Choudhry, Kilabuk, & Shrank, 2011). It covers many different topics, such as the features of health groups (Bender, Jimenez-Marroquin, & Jadad, 2011) and how social media are used in relation to specific diseases (Shaw & Johnson, 2011). Studies generally focus on social networking sites (SNS) such as Facebook (Greene et al., 2011), Twitter (Thackeray, Neiger, Burton, & Thackeray, 2013), and those built exclusively for healthcare users to share their experiences (Wicks et al., 2010) or review healthcare providers (Reimann & Strech, 2010). Additionally, attention has been directed to the use of personal blogs (Shah & Robinson, 2011) and content communities such as YouTube (Prybutok, 2013).

This increasing research attention reflects an increase in social media utilization by healthcare users (Antheunis et al., 2013; McCaughey et al., 2014). Early work on social media in healthcare has shown that healthcare users engage in providing and receiving emotional and informational support (Maloney-Krichmar & Preece, 2005). In regards to emotional support, they rely on the experiences and emotional comfort of others throughout their disease (Antheunis et al., 2013). This enables them to share their emotional difficulties (Menon et al., 2014). In particular, they share their emotions with other healthcare users who are coping with

similar problems. Other reasons given for the use of social media for emotional support include maintaining relationships with others (Ziebland & Wyke, 2012).

However, healthcare users not only receive emotional support but also supplement the information received from healthcare professionals (Rupert et al., 2014). Furthermore, if they are in need of extra information about their disease and treatment options, they can learn from the healthcare uses who have already dealt with the disease for a significant amount of time. For example, they can receive advice about treatments (Setoyama et al., 2011), and they can share their personal experiences, and any other relevant information about their disease (Chiu & Hsieh, 2013). They also ask many questions to strengthen their knowledge about their particular disease (Coulson, 2013). In this way, they are using social media for health-related informational support.

This use of social media can have significant implications for healthcare users, as different patterns of online support may lead to different health outcomes (Yan & Tan, 2014). Social media use by healthcare users can also be an aid to healthcare providers as a tool to strengthen the organizations' market position (McCaughey et al., 2014). It can also stimulate brand building and improve service delivery (Williams, 2011). Yet, the main reason that healthcare users join social media health networks is their dissatisfaction with the healthcare provision they receive in regards to their emotional and informational needs (Rupert et al., 2014).

Recent evidence suggests that healthcare users communicate online not only with other healthcare users but also with healthcare providers (Moorhead et al., 2013). Accordingly, we see an increase in the use of social media by some healthcare providers, in particular on social media platforms such as YouTube, LinkedIn, and Facebook (Van de Belt et al., 2012). However, this user-to-provider communication via social media is currently relatively limited.

Healthcare providers often use social media for marketing purposes, and to communicate with other healthcare providers (Antheunis et al., 2013). At present, only a relatively small number of healthcare providers engage in two-way communication with healthcare users via social media (Huang & Dunbar, 2013). Furthermore, when healthcare providers do initiate platforms and use social media to communicate with healthcare users, the latter group appears to be reluctant to contribute, whereby most content is generated and shared by the providers themselves (Miller & Tucker, 2013).

Taken together, this literature does not, yet, offer a clear picture of the nature of social media enabled interactions in healthcare. In particular, it does not inform us about the specific types of interactions healthcare users engage in via social media. One step forward in this regard is a taxonomy of the interactions taking place via social media where healthcare users communicate together with providers. To be able to categorize different interactions, we turn to the dimensions of control and generativity, which are important from the healthcare and the technology aspect.

3.2.4 Taxonomy dimensions

Control and generativity of interactions in healthcare

Our motivation for this chapter is to provide a deeper understanding of social media enabled interactions in healthcare, which can also serve as a foundation to understand the potential impact in offline interactions between healthcare providers and users. In regards to this, we elaborate on the dimensions, which help us categorize online interactions, namely scope of control and generativity.

Traditional information exchange in healthcare takes place through the solution shop model (Hwang & Christensen, 2008). As such, it reflects offline interactions between healthcare

providers and users. With such interactions, there is an asymmetrical relationship between healthcare providers and users, whereby all parties engage in provider-centered behaviors (Stewart, 2001). Healthcare user participation in such a relationship may be somewhat limited, and it usually involves receiving a diagnosis and carrying out basic tasks, which are often delegated from provider to the user (Potter & McKinlay, 2005). This traditional form of communication between is typified by a highly paternalistic and formal means of control.

More recently, many healthcare providers encourage a different type of information exchange, as shared decision making and patient autonomy have come to the fore (Elwyn et al., 2012). In this system, healthcare users become more involved in their care and form partnerships with healthcare providers. Overall, these interactions remain formal regarding control, which is a critical component for understanding effective communication between two parties (Street, Krupat, Bell, Kravitz, & Haidet, 2003).

With the advent of social media, the online knowledge sharing process represents a shift from a centralized to a decentralized process, as individuals can post information whenever they want in informal and formal ways (Kane et al., 2009). Therefore, the distinction between formal and informal control becomes an important aspect of social media enabled interactions. By control, we refer to formal control as a more paternalistic approach and limited healthcare user involvement in the communication and decision-making. In such communication, a strict hierarchy between the actors is apparent. Conversely, online sources allow healthcare users and healthcare providers to exchange information quickly (Broom, 2005b; Eysenbach, 2008) and in informal ways. This is done through the collective building of lay knowledge and promoting online forms of self-help. In this way, the communication between parties is much more informal in the online environments. Overall, the aspect of control is essential for considering

how different types of interactions on social media may potentially affect the relationship between healthcare users and their healthcare providers.

Another important concept for understanding online interactions and potential changes they bring is generativity. Generativity is a system's capacity to produce unanticipated change through unfiltered contributions from broad and varied audiences (Zittrain, 2008). In relation to digital technologies, generativity enables information sharing to become inherently dynamic and flexible (Yoo, Boland, Lyytinen, & Majchrzak, 2012). Due to the re-programmability of digital technologies, new capabilities can be added after a product has been designed and produced. How much a system or a platform allows others to contribute depends on technological functions and social behavior (Zittrain, 2008). For others to contribute to the platform, it is important to determine how the system relates to its users and how the users relate to the platform owner. Two important social aspects of the generativity in social media are processes and interactions, which may influence the outcomes of the platforms (Osch & Avital, 2010). Communication and interaction between users in social media are of value because of the degree to which they can expand their knowledge depends on the members themselves. In terms of online sharing, generativity represent “ways of knowing” that come about through transformative communication, where participants are mutually transformed by the process of communication with the cultural messages of others, and hence go beyond the common body of knowledge, or “expand the ways of knowing” (Pea, 1994). Each user offers resources for transforming the practice and meaning of others, which is a key aspect of the online interactions, in particular in co-construction of knowledge. Hence, this reinforces the importance of looking into social aspects of generativity. Thus, we argue that social media enabled interactions should be associated with generative use rather than be treated simply as technology objects. Therefore, we consider technology and actors in assessing the generativity level of interactions. Thus, by

generativity, we consider the extent to which the interactions through the constellation and behavior of users as well as technological affordances enable the emergence of new interactions and topics.

3.3 Methods

3.3.1 Research design

We adopted a mixed methods approach in our data collection and analysis. We used a sequential approach in which we first collected and analyzed qualitative data, which then informed our quantitative data analysis (Venkatesh, Brown, & Bala, 2013). In this way, we followed an inductive approach for developing a taxonomy, which is suited to the IS field (Nickerson, Varshney, & Muntermann, 2013) and contributes to providing valid results (Creswell, Klassen, & Clark, 2011). A key social media feature is the creation and exchange of user-generated content (Kaplan & Haenlein, 2010), for which qualitative content analysis is appropriate. Content analysis is a process to summarize raw data, and it relies on inductive reasoning with themes and categories emerging from the data (Hsieh & Shannon, 2005). In the subsequent step, to validate and refine our inductive findings, we employed statistical cluster analysis. This method makes use of various quantified characteristics of the data, such as the themes and categories identified in the content analysis, and determines a set of clusters, or groups, whereby the data points in the same cluster are more similar to each other than to those in other clusters (Hair, Black, Babin, & Anderson, 2010). Moreover, we followed a good example of other IS scholars by combining qualitative and quantitative approaches to develop our taxonomy (Vaghefi, Lapointe, & Boudreau-Pinsonneault, 2017).

3.3.2 Data collection

We selected six different categories of social media, taken from the taxonomy of social media categories proposed by Kaplan and Haenlein (2010), and searched for four cases of social media platforms per category. We guided our purposive selection in order to ensure variation and a range of perspectives relating to our research question. Therefore, we varied our case selection per category in two ways. First, we searched for general health versus condition-specific social media platforms. There is a clear difference between platforms covering many general health topics and social media health communities focused on a single health condition (Greene et al., 2011). Second, we searched for user-initiated versus provider-initiated platforms. In user-initiated platforms, the participants may easily express themselves if they feel comfortable among fellow sufferers. In provider-initiated communities, healthcare users are more reluctant to contribute content, which is most often generated by healthcare providers (Miller & Tucker, 2013). Furthermore, we selected cases that are popular, according to their participation levels, as well as notable cases, which are prominent in lists of social media healthcare platforms on different sites. Although an attempt was made to analyze four social media platforms per category, we were not able to locate provider-initiated collaborative projects on a specific health condition. We were also only able to locate a single virtual world health game in which we were able to observe what the users could do. Therefore, the social media platforms selected amounts to the 20 shown in Appendix B.

We observed and collected the data from our cases by selecting posts and comments from blogs, social networking sites, content communities and collaborative projects. Within each of these categories, we collected 400 posts and comments. We were not able to collect the content of the virtual game worlds and virtual social worlds. This is because there was no place for participants to exchange content publicly.

3.3.3 Data analysis

To analyze data, we followed three phases, which we elaborate below, and which we present schematically in figure 3.2. In our first phase, we selected and coded parts or entire posts and comments. In this way, we initially arrived at 1727 quotes. We started the analysis with theoretical coding for the topic of interactions (Glaser & Strauss, 1967). For the nature of communication, we were broadly guided by Interaction Process Analysis (IPA) to classify the communication based on the nature of communication (Bales, 1950). We applied codes to each instance of communication, which indicated the theme and nature of the communication. In this process, we followed the principle of theoretical saturation (Eisenhardt, 1989; Glaser & Strauss, 1967). This means that we continued to analyze data until we reached the point that more quotes did not lead to new thematic codes or codes for the nature of communication. In total, this analysis produced nine distinct thematic codes and six codes for the nature of communication, which was reflected in either the entire post or comment or in part of it. We removed the quotations that were classified as non-health. Thus, our final sample of quotations was reduced to 1566. The review of our codes is provided in the Appendix C. Following our coding process, we engaged in the process of analytical induction (Glaser & Strauss, 1967). In this way, we discovered concepts and relationships using collected quotations on themes and nature of communication, which helped us to get first insights into types of interactions.

In our second phase of data analysis, to uncover archetypical interactions, we turned to cluster analysis. Cluster analysis is a way of grouping a set of objects or observations within distinct groups, where the observations in one group are more similar to one another than to those in the other groups. We first recoded our 1566 quotes for the topic of the quote, the nature of the communication, the actor involved, and the platform characteristics. Besides these distinguishing characteristics for determining the clusters, we also recorded platform features

that helped us with the interpretation of clusters. These features are the category of social media, the purpose of the platform, and initiator of the platform. We applied hierarchical cluster analysis using Ward's method with Euclidean distance, which is widely used and recommended (Borgen & Barnett, 1987; Hair et al., 2010). With cluster analysis, there is no firm consensus on how to choose the optimal number of clusters. We utilized the elbow effect, which is a visual method to identify the solution whereby adding extra clusters does not provide new information (Kodinariya & Makwana, 2013), as shown in Appendix D. Furthermore, an ANOVA test provided an opportunity to interpret the results meaningfully and to assess the quality of the clusters (Bapna, Goes, Gupta, & Jin, 2004). Thus, we compared the clusters' mean scores on the variables through one-way ANOVA testing to observe the key differences between our clusters and to confirm that our clusters are significantly different from each other. Through this process, we arrived at five clusters representing archetypical interactions of health-related social media use.

In our third and final methodological step, we engaged in an iterative process to derive a taxonomy of health-related social media interactions. We based our choice of dimensions for the taxonomy on the literature describing the type of control and generativity of interactions as we elaborated in our findings. We used our codes, archetypes, and statistical analysis to categorize each archetype in the taxonomy as shown in Figure 3.2.

In sum, we engaged in three empirical stages to arrive at our taxonomy. The process of three stages of empirical analysis is shown in Figure 3.2, and Appendix E provides a more detailed overview of each stage.

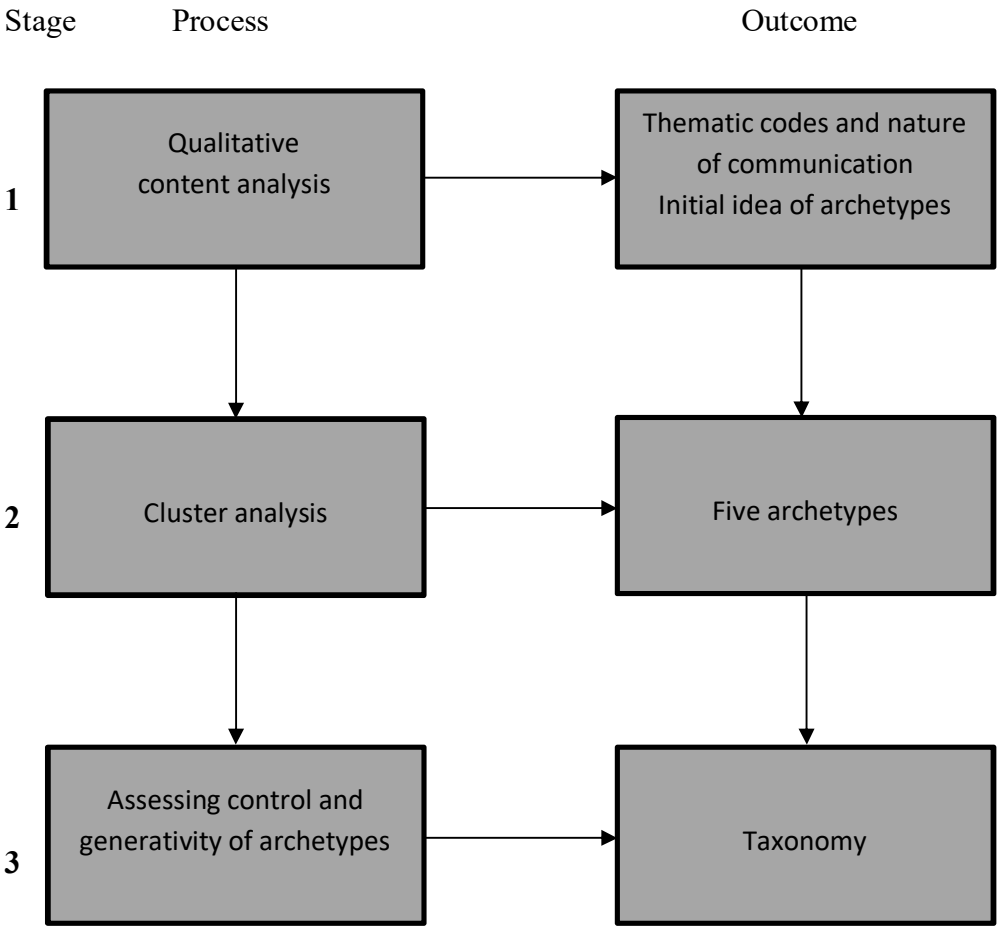

Figure 3.2 Data analysis process

3.4 Results

In this section, we present our five archetypical interactions that were the result of our cluster analysis, based on the topics and nature of communication, which we observed through qualitative content analysis. We describe and illustrate these archetypical interactions below and present the summary in Table 3.1.

3.4.1 Personal health condition resolving

This archetypical interaction is initiated by healthcare users and directed toward healthcare users and providers. As compared to other interactions, this archetypical interaction involves a higher share of healthcare providers. The healthcare users describe their symptoms in detail and pose concrete questions to the providers. These interactions always focus on personal health conditions. A distinctive feature of these interactions is that the communication between the healthcare users themselves and with providers goes on until the healthcare users are satisfied with an outcome. Therefore, they are often in-depth and have a corrective character. These interactions involve expressing and asking, and they are carried out in an instrumental way. They reflect a higher level of control in communication by providers who participate in the discussion and healthcare users often use official titles when addressing the providers. On the other hand, the interactions have the very deep scope of interactions and often go into details of somebody's condition. A conventional example of this archetypical interaction, from the MedHelp platform, is provided below:

Post (user): *….now I've been experiencing heart palpitations , weakness , fatigue , dizziness , and very rarely shortness of breath , loss of appetite I'm afraid…. why do I have all these other symptoms?*

Comment (provider): *I might recommend checking your pulse whenever you have these spells to see whether you have a fast or irregular heart rate….*

3.4.2 Knowledge-building through teaching

These interactions are mostly instrumental and concern general topics. They have the highest share of healthcare providers when compared to other archetypical interactions. In these types of interactions healthcare providers and healthcare users who make posts act more as "teachers" and provide educational content. The goal seems to be building specialized knowledge on the topics in question and those who post seem to have a high level of expertise regarding the topic. The content is addressed to healthcare users who react to it by showing appreciation for it and sometimes initiate discussion with those providing the content (e.g. providers or users). In addition, healthcare users provide their opinions on the subject and discuss among themselves and with those who posted the content. Often, the discussions refer to the role of different providers and policies in regards to general health or treatments of a particular condition. These discussions often pertain to health policies on the management of chronic diseases and reflect preventive and corrective approach to dealing with one's health. The providers and users who make posts always address healthcare users in an instrumental way, attempting to address health topics in a general way as opposed to discussing personal experiences. Therefore, they are directed toward corrective and preventive measures for dealing with one's own health. Interactions reflect formal hierarchy between those who act as "teachers" and users who follow and comment on their posts. Discussions are rather broad regarding the scope of interactions. A standard example of this interaction is provided below:

Post (provider): ….*That name is dermatographia urticaria, usually just called dermatographia or dermographism (literally "writing on the skin"). It's a type of "trauma-induced urticaria," but the trauma in this case can be ...*

Comment (user): …*Very interesting article and it is kinda interesting that these allergy related textures can be created on skin with mild scratching*…

3.4.4 Informing about healthcare products

This archetypical interaction takes place mainly among healthcare users. The healthcare users provide detailed information on different healthcare products. Such interactions often take place in an instrumental way. They rarely have a social-emotional component, such as when the users express anger toward a particular health product. Interactions are mostly very general and do not concern personal experiences, but rather objective information or a general review of the health product that those who post have not personally used. Such interactions are in-depth and go into details about the products. These interactions reflect a corrective character in dealing with one's health. They are very informal, and participants address each other freely and openly. A standard example is shown below:

Post (user): *....announced availability of a new FDA-approved generic test strip, and at the same time, we got word that the green-colored GenStrip alternative test strip…*

Comment (user): *...the UniStrip1 test strips are cleared by the FDA for use with the LifeScan OneTouch Ultra, Ultra2, UltraMini and UltraSmart*

3.4.5 Empathizing with fellow sufferers

These interactions mainly take place between healthcare users. A healthcare user who talks about his or her health condition and experiences usually initiates the interactions. Other healthcare users engage in the interaction by empathizing with the original user and expressing their emotional support. Such interactions are mainly focused on the personal conditions of the healthcare users who initiate them. The content is usually expressed in a social-emotional way

with the healthcare users, showing solidarity and raising the status of the healthcare user who initiated the discussion. In cases where providers participate in the interactions, it is usually the posts of the providers that are aimed at providing emotional support to healthcare users. Interactions are focused on preventive and corrective ways of dealing with one's health. Interactions are very informal and do not indicate high hierarchy between users who interact with each other. They do not go into depth and usually end fast. The following example from the platform, Lose weight Jo!, illustrates this archetype:

Post (user): *This is so me! Sharing photo: I work out because it is good for me. Also, because I like to eat. A lot.*

Comment (user): *Yep I'm with ya sista!! :)*

Post (provider): *WMTW-TV tells the story of 6-month-old Boston Children's patient Sam Sturtevant who had a liver transplant at 30 days old.*

Comment (user): *Pray he is doing ok. He's adorable!!!!*

3.4.6 Lifestyle support

These interactions are mostly started by healthcare users and aimed at other users. They have an educational character that is reflected through explanations of, for example, how to do specific exercises. The interactions also include offers of advice on how the exercises can affect one's weight and contribute to a healthy lifestyle. The healthcare users attempt to guide others and promote a healthy lifestyle by provoking discussion about it. In doing so, they talk about and present their experiences as well as general topics. They express and ask questions on the topics. Providers initiate a small proportion of the interactions. The healthcare providers promote a healthy lifestyle through fitness and food-related topics. Users and providers cover

these issues and focus on the prevention of health problems. The posts of this archetype mainly reflect an instrumental way of communication in which users and providers want to transfer information explicitly and objectively. Interactions are relatively informal with a low hierarchy between "gurus" who promote healthy lifestyles and their "followers" who engage in communication. On the other hand, users discuss personal experiences and general topics along with the interactions themselves while easily switching from one topic to another. Thus, these interactions remain broad in regards to the scope. Below is a standard example of this archetype from the Everydayhealth platform:

Post (user): *https://www.youtube.com/watch?v=TFssp4kG_8M* – video showing exercises for arms.

Comment (user): *Thank you Holly! Yes, this is helping me to tone my arms.*

Table 3.1. Summary of archetypical interactions

Interaction type	Personal health condition resolving	Knowledge-building through teaching	Informing about healthcare products	Empathizing with fellow sufferers	Lifestyle support
Focus	Personal conditions and getting advice from providers	Building specialized knowledge through teaching users	Reviewing healthcare products	Providing emotional support	Guiding and promoting healthy lifestyles
Actors	Provider-to-user; user-to-user	Provider-to- user; user-to-user	User-to-user	User-to-user	Provider-to-user; User-to-user
Nature of interactions	Instrumental and personal	Instrumental and general	Mostly instrumental and general	Social-emotional and personal	Both social-emotional and instrumental, personal and general
Prevalent categories	Social networking sites, content communities, and blogs	Blogs and collaborative projects	Blogs	Content communities, Social networking sites	Social networking sites, content communities
Purpose of interactions	Corrective	Preventive/Corrective	Corrective	Corrective/ preventive	Preventive

Table 3.2. ANOVA results (complementary variables)

Variable	Personal health condition resolving	Knowledge-building through teaching	Informing about healthcare products	Empathizing with fellow sufferers	Lifestyle support	ANOVA
Platform characteristics	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	F
Blogs	.22 (.42)	.43 (.49)	.45 (.49)	.29 (.45)	.24 (.42)	15.28*
Social networking sites	.24 (.41)	.18 (.38)	.17 (.37)	.44 (.49)	.24 (.42)	21.25*
Collaborative projects	.26 (.44)	.14 (.34)	.35 (.47)	.00 (.00)	.22 (.41)	40.71*
Content communities	.28 (.44)	.25 (.43)	.03 (.17)	.27 (.44)	.30 (.45)	17.60*
General vs. Specific	.49 (.50)	.55 (.49)	.60 (.49)	.54 (.49)	.51 (.50)	2.11

* $p<0.05$

3.5 Taxonomy

To develop a taxonomy of healthcare users' social media interactions, we categorize the interaction archetypes along two dimensions, namely control and generativity as elaborated on in our theoretical background. Figure 3.3 illustrates our taxonomy with our archetypes.

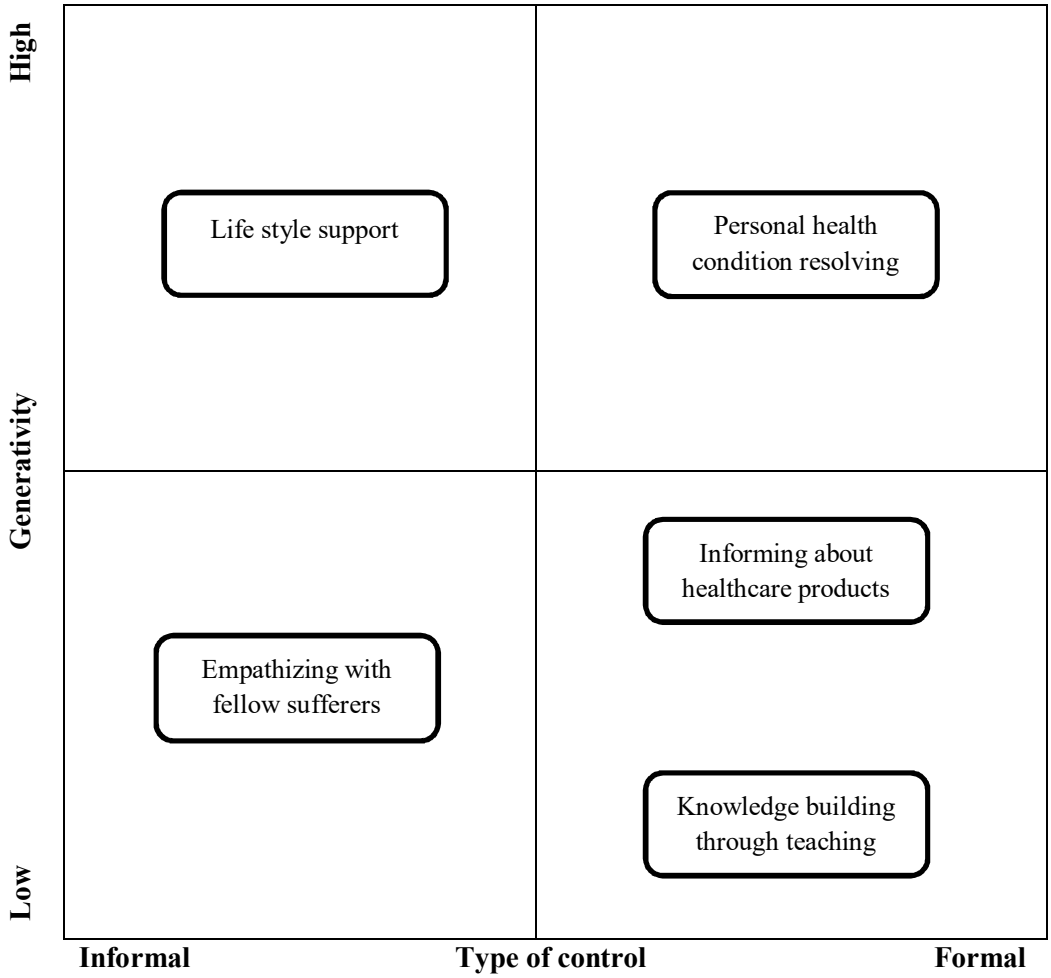

Figure 3.3. Taxonomy of social media enabled interactions in healthcare

3.6 Discussion

In our first part of the discussion, we address each archetypical interaction in two ways. First, we discuss different interactions in regards to extant literature. Second, we discuss potential effects of each archetypal interaction on the relationship between healthcare users and healthcare providers. Namely, we focus on two aspects of the relationship. In the final part of our discussion, we address the theoretical and practical implications of our research.

In *resolving personal health condition*, we observe that these interactions mostly take place on content communities and social networking sites with the purpose of asking precise questions on health conditions, most often in regards to chronic diseases. This extends the findings of Andersen (2012) who reported that the healthcare users utilized social media to make appointments and ask questions to providers. Our findings illustrate that healthcare users communicate with providers to ask health-related questions on their specific conditions, but also rely on other healthcare users with this respect. This interaction has a formal type of control, and it is high on generativity. Having a formal type of control resembles offline healthcare provider-user interactions in which healthcare providers are leading actors. At the same time, the high generativity of these interactions enables the emergence of new discussions and may extend healthcare users' knowledge on different aspects of their conditions. This means that the information asymmetry between healthcare providers and healthcare users is reduced. Thus, this may affect the provider's task-focused behavior in which providers represents those with crucial expertise. When healthcare users can obtain knowledge on different topics about their disease, they may increasingly interact with their healthcare provider during clinical interactions and become more involved in the decision making process (Colineau & Paris, 2010). Hence, we propose that the healthcare users will take a more proactive role in this aspect of the relationship with healthcare providers.

In interactions characterized as *knowledge-building through teaching,* interactions somewhat reflect earlier findings (Antheunis et al., 2013; Chou et al., 2013) that social media are used for health education and knowledge building. However, we also provide a clear overview of how and between whom this type of communication transpires across different categories of social media. In particular, we supplement the earlier literature by showing these archetypical interactions to be prevalent in blogs and content communities and take place amongst healthcare users but also between healthcare providers and users. The interactions have a formal type of control as initiators solely direct the topics, and the interactions are low on generativity as they do not encourage the emergence of interactions on new and different topics. Although formal control characterizes them, the interactions enable healthcare users to grasp the highly specialized knowledge of the health topics that are posted, thus covering most of the issues addressed during healthcare provider-user interactions. Hence, this archetypal interaction may reduce the information asymmetry between healthcare providers and healthcare users. This means that the healthcare users may become more proactive, in particular when it comes to the task-focused behavior of healthcare providers. Thus, we propose that these types of interactions lead to a more balanced relationship between healthcare users and healthcare providers regarding task-focused issues.

Informing about healthcare products occurs mostly in blogs and collaborative projects. Whereas Ziebland and Wyke (2012) suggest that people mainly use specialized health platforms to discuss their health products and providers, our archetype does not appear to be necessarily limited to a particular category of social media but, instead, spans across blogs, content communities, and social networking sites. The interactions have a formal type of control and are low on generativity. Having high scope of control and low generativity coupled with a limited number of users means that the healthcare users get explicit knowledge on a particular aspect of their health condition. Regarding the relationship between healthcare users and

healthcare providers, healthcare users may be able to reduce information asymmetry in regards to this particular aspect. The provider's authority in prescribing types of medicines may be questioned. Thus, we propose that the healthcare users will become more empowered regarding choosing the medicine or treatment that they believe is appropriate.

Interactions characterized as *empathizing with fellow sufferers* are in line with earlier studies on the fact that the healthcare users are making use of social media to receive emotional support (Antheunis et al., 2013; Moorhead et al., 2013; Ziebland & Wyke, 2012). This transpires between healthcare users. Actually, we show that these archetypical interactions involve mostly healthcare users. We also reveal that the interactions are not exclusive to social networking sites, but notable also with content communities. These interactions have an informal scope of control and low generativity. The informal scope of control implies relaxed communication between healthcare users. This means that healthcare user-to-user online interactions may substitute any social-emotional part of the medical encounter in the relationship between healthcare users and healthcare providers. Low generativity implies that these interactions do not enable the generation of many new topics or avenues of discussion, and stay very specific. This means that the knowledge sharing among different users is somewhat limited as they do not share explicit information on how to deal with specific diseases, which would be easily grasped as a form of explicit knowledge. Hence, the information asymmetry that they can reduce between themselves and healthcare provider is limited. Thus, we propose that the social-emotional part of the relationship between healthcare users and healthcare providers will be reduced for users who engage in this type of online interaction.

The *lifestyle support* interactions mostly take place in content communities, which afford easy sharing of different exercises and lifestyles. A similar pattern of use was broadly described by Hamm et al. (2013) stating that the healthcare users often use social media to share their experiences about weight loss and lifestyle. These interactions have an informal type of control

and are high on generativity. Informal control enables easy and relaxed communication of users with lifestyle support "gurus", which leads to different types of interactions on lifestyle as generativity is high. This means that healthcare users build their knowledge on some topics that can help them be proactive about their health. As it is focused on preventive actions, these actions may not directly affect the relationship between healthcare users and healthcare providers, which is corrective. Yet, these "gurus" who interact online and are seen as providing high-quality advice, may gain in reputation and attract positive feedback and gain the attention of non-patients and patients. Thus, we propose that their level of influence may increase and potentially threaten the traditional, offline healthcare providers, thus decreasing healthcare users' reliance on offline interactions.

3.6.1 Theoretical implications

Our key findings are five archetypical interactions of health-related social media use. With our findings of five archetypical interactions, we revisit the long-standing idea of informational and emotional support in healthcare (Schaefer, Coyne, & Lazarus, 1981). Our findings indicate that the concept of informational support in healthcare may not be as generic as indicated by current literature. It consists of distinct and unique attributes, such as those indicated in our three archetypes, namely resolving a personal health condition, and informing about healthcare products and knowledge-building through teaching. This differentiation of the simple idea of informational support has not been previously described.

Furthermore, we uncover a new type of online health-related use of social media, which we call lifestyle support. Whereas earlier research and the broad concepts of emotional and informational support have mainly investigated contexts in which healthcare users already suffer from some form of ill-health (Eriksson & Lauri, 2000), we find that our lifestyle support interaction is a distinct type of use in the healthcare context.

Finally, we place our five archetypes in a taxonomy, which is another novel result of this chapter and which goes some way to answering the call for research on social media in healthcare (Agarwal et al., 2010; Fichman et al., 2011). We enrich the literature by showing what interactions take place in different social media categories, between whom and how they can be categorized. In this way, we built on existing literature on the use of social media in healthcare (Andersen et al., 2012; Chou et al., 2013; Ziebland & Wyke, 2012). We have shown that some interactions may be specific to specific categories of social media and we indicate the actors who participate in these interactions. For example, an interaction type *empathizing with fellow sufferers* mostly takes place in social networking sites such as *Facebook* and involves healthcare users. Moreover, our findings also shed more light on the recent research on how knowledge is built within social media health communities (Faraj et al., 2016). Overall, our work facilitates a better understanding of the use of social media, and it provides a foundation for future work in regards to the effects on offline interactions. Furthermore, our taxonomy enables theorizing about social media enabled interactions along two dimensions, which are important from the healthcare provider-user interaction perspective as well as the social media/technology perspective.

We also theorize on the process under which certain social media enabled interactions may have potential effects on the relationship between healthcare users and healthcare providers. First of all, the traditional role of healthcare providers entailed them being experts who provide knowledge to healthcare users and interpret the their symptoms, which was a result of information asymmetry between healthcare providers and users (Arrow, 1963). However, we find that social media enables users to discuss and recommend solutions to each other in the form of online communication. Although healthcare user online support is not a new concept, we provide in-depth insights into different interactions and identify specific types of use.

3.6.2 Practical implications

Overall, social media enabled interactions may potentially affect the task-focused part and the social-emotional part of healthcare provider-user interactions. In particular, the interactions that enable specific knowledge sharing may lead to a more balanced, reciprocal relationship between healthcare users and healthcare providers when it comes to the task-focused issues. This may be enabled by the mechanism of building explicit user knowledge on some topics. On the other hand, one of the interactions, namely *empathizing with fellow sufferers* may further reduce the social-emotional tasks of providers. These findings may have implications for the engagement of healthcare providers and the design of their social media platforms. Social media have been shown to be a channel through which strong inter-personal influence can take place (Cha, Haddai, Benevenuto, & Gummadi, 2010). If promoters of specific ideas become very popular amongst users, they may have a strong influence on the behavior of their online followers. Healthcare providers can exploit this opportunity if they set up their own social media networks and use their credibility and trustworthiness to attract users. In particular, healthcare knowledge is now being distributed widely on social media by a large number of non-specialists who are sharing scientific and non-scientific knowledge. Thus, the quality of health-related information on social media is very diverse (Sillence, Briggs, Harris, & Fishwick, 2007). Moreover, the bulk of information and its diverse quality may lead to information overload in which healthcare users cannot process and utilize all the information adequately. Hence, healthcare providers could take a more proactive role by providing different designs for different types of online interactions. Furthermore, by actively engaging in the communication with healthcare users and answering their questions online, they can help them in the sense-making process, and by distinguishing information from misinformation.

3.6.3 Future research

Although our initial idea was to include all six categories of social media in our data collection and analysis, we had to exclude virtual worlds as we were unable to access the content of user interactions. Given that virtual worlds have a good potential in transferring medical knowledge (Boulos, Hetherington, & Wheeler, 2007), our results may not provide a full picture of this social media category. Furthermore, virtual worlds offer an opportunity to understand personal characteristics through avatars (Suh, Kim, & Suh, 2011). Thus, we propose that future research addresses user to user and provider to user interactions in virtual worlds, which could improve our understanding of social media enabled interactions as well as their potential effects on offline interactions. Besides this limitation, the scope of this chapter is to create a taxonomy rather than to use it to assess the effects of the different archetypal interactions empirically. Future research is needed to build upon this work and to assess the strategic implications thereof.

Chapter 4: How chronic disease patients use social media and reshape their roles[3]

Abstract

This chapter examines how chronic disease patients' use of social media can drive changes in their roles in the healthcare process. Social media provide these patients with an opportunity to communicate with a large number of their peers and to share their experiences. In doing so, patients can understand their conditions better, and thus change their behavior as well. This is particularly important for chronic disease patients as their conditions are closely related to how they view themselves and their roles. We study two social media health communities for chronic disease patients, namely diabetes, and brain injury. This chapter reveals that patients use social media in ways that change who they are and what they do in their relationship with healthcare providers. In particular, our findings show that chronic disease patients go from understanding their condition to also being understood by others; engage in collective learning and diagnosing; build a sense of control and thus also get empowered. We find as well that patients substitute part of their healthcare provision with social media use and create new emerging partnerships with doctors. First, we contribute to health information technology (HIT) scholarship by developing our understanding of how chronic disease patients use social media as a form of HIT to change their roles. Second, this chapter contributes to the literature on the relationship between patients and healthcare providers and reveals how social media afford changes in this relationship through patient use. Third, it reveals how different types of chronic diseases and corresponding use of social media may affect patient identity construction and role of the patient in different ways.

[3] This chapter was written together with Albert Boonstra, David Langley and Emmanuelle Vaast. A previous version of this chapter was presented at European Conference on Information Systems (2016).

4.1 Introduction

According to the World Health Organization (WHO), chronic diseases, such as diabetes, affect about 347 million people worldwide and are predicted to become the seventh leading cause of death in the world by the year 2030 (World Health Organization, 2015). Chronic diseases represent complex conditions influenced by various contextual factors. The management of chronic diseases is a major challenge for healthcare systems (Funnell & Anderson, 2004). Thus, today's healthcare systems face difficulties in coping with the increasing demands placed on them. Chronic patients, in particular, suffer from high complication rates and a lack of well-coordinated care support (Schoen, Osborn, How, Doty, & Peugh, 2009).

The care for patients through the healthcare consultation process between doctor and patient has traditionally been a cornerstone of the medical practice. It is a formalized process of interaction in which the patient seeks advice from a doctor, and the doctor works toward providing a solution to the patient's problem. This process has at times been called a "*solution shop*" (Hwang & Christensen, 2008). It has long been characterized by face-to-face interactions between doctor and patient as the primary way to exchange information (Gottschalk & Flocke, 2005). Thus, doctors have often been the main if not only source of information for patients (Hellawell, Turner, Le Monnier, & Brewster, 2000), leading to longstanding information asymmetry between doctors and patients (Pilnick & Dingwall, 2011).

To cope with these issues and to address a lack of coordinated support and rising costs, healthcare systems have increasingly started to rely on new digital initiatives, especially for chronic diseases (Agarwal et al., 2010; Tani et al., 2009). As recently proposed by Oborn and Barrett (2016), digital health and patient engagement initiatives hold a high potential to change health service delivery. Strong et al. (2012) also suggest that new technologies may be a key part of the solution for management of chronic diseases. In particular, healthcare has experienced a high proliferation of social media use (Kane et al., 2009). Interactions afforded

by social media enable patients to move from one-to-one and one-to-many to many-to-many communications (Hawn, 2009). In this way, patients may adjust their use of social media to exchange health advice and even to self-manage their condition (Lederman et al., 2014; Merolli et al., 2015). Sharing information and experiences through social media also enables the creation of new models for healthcare (Kallinikos & Tempini, 2014). It helps patients address issues that they cannot deal with in a traditional medical setting (Schaffer, Kuczynski, & Skinner, 2008). Furthermore, patient interactions afforded by new technologies such as social media may even reshape how healthcare is provided (Hawn, 2009).

These developments could change the roles and identities of patients (Fox & Ward, 2006). Agarwal et al. (2010) suggest that such changes may take place when patients give more credibility to information received from their peers on social media than to information provided by their doctor. Moreover, social media-enabled interactions with fellow patients can affect how individuals construct their identity (Zhao et al., 2008). This is particularly important for chronic disease patients because their lives and identities can be significantly affected by the disease (Asbring, 2001).

Despite the importance of the patient perspective and increasing patient interactions via social media, there remains little scholarship on this in either Health Information Technology (HIT) or the social identity literature. On the one hand, the HIT literature has traditionally focused on topics such as privacy concerns, interoperability, and resistance to change (Romanow et al., 2012). It has paid less attention to the patient perspective (Agarwal et al., 2010). Because of this, some scholars have called for more work on the role of patients as e-health users, especially in the case of chronic diseases (Wilson & Strong, 2014). On the other hand, the social identity scholarship on healthcare has mostly focused on changes in the roles and identities of doctors (Chreim, Williams, & Hinings, 2007; Mishra, Anderson, Angst, & Agarwal, 2012; Pratt et al., 2006; Reay et al., 2017). For example, Mishra et al. (2012) showed how the identity of doctors

influenced their adoption of electronic health records. Others such as Reay et al. (2017) focused on how the roles and identity of doctors changed through their interpretation of multiple institutional logics.

Despite this mostly one-sided nature of research attention given to the relationship between patients and doctors, the significance of the patients' role has recently been acknowledged (Reay et al., 2017) and IS scholars have called for more research from the patients' perspective (Agarwal et al., 2010). This is all the more important because patients are key actors in the healthcare process (Gottschalk & Flocke, 2005) and their and doctor's perspectives in managing chronic disease may differ (Essén & Oborn, 2017). Yet, the HIT and social identity scholarships have so far paid little attention to the patient perspective and to the changes in patients' roles that may take place through their interactions via new technologies such as social media.

Such research is especially warranted in the context of chronic disease patients for several reasons. First, chronic diseases strongly influence patient identity (Asbring, 2001). Second, opportunities afforded by social media represent a new avenue for the management of chronic diseases and the development of doctor-patient partnerships (Seeman, 2008). Third, although chronic diseases are often grouped and contrasted to acute health problems, how patient identities are reshaped may well differ depending on the type and the nature of the chronic disease (Macdonald et al., 2016).

The objective of this chapter is thus to take on the patient perspective and to examine how chronic disease patients' interactions, afforded by social media, reshape their identity and roles. In this endeavor, we focus on two related aspects of patients' identity, namely "who they are" and "what they do" (Pratt et al., 2006). Accordingly, we pose and provide elements to address the following research question: *How does social media use by chronic disease patients afford changes in their identity and their roles in relation to healthcare providers?*

To address this question, we investigate in-depth two social media health communities for chronic disease patients with diabetes and brain injury. We chose two contrasting conditions as such paired selection provides an opportunity to understand distinctions and interplay between the cases (Eisenhardt, 1989; Pettigrew, 1990; Yin, 2003).

This chapter contributes to HIT scholarship by studying social media interactions and by taking the patient perspective, which addresses recent calls for research for such focus (Agarwal et al., 2010; Fichman et al., 2011). This chapter also contributes to scholarship by providing new insights into how interactions via social media can affect relationships between patients and doctors regarding their roles. Furthermore, the chapter contributes to a better understanding of how the identity of chronic disease patients is affected by the interplay of their specific chronic disease and their use of social media. In particular, we point to how patients' identities are uniquely constructed as a result of their specific disease and their online interactions afforded by social media. This chapter also holds practical implications by providing a better understanding of social media use by chronic disease patients, which can assist healthcare providers and policymakers.

4.2 Theoretical background

4.2.1 Patients' roles and identity

Social identity refers to people's self-definition on the basis of group membership (Tajfel & Turner, 1986). Social identity is not fixed but changes in an ongoing manner in response to social interactions and feedback from others (Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). In this chapter, we focus on two central questions of one's identity, namely "who are we" and "what we do" (Pratt et al., 2006), and hence take a broad view on social identity. This focus captures one's self-view as well as one's roles, which is particularly important when considering chronic disease patients. As such, identity helps people interpret their experiences and adjust to changes in their social environment (Markus & Wurf, 1987). This chapter focuses

on the relational identity for chronic disease patients regarding patient-to-patient and patient-to-doctor relations. Such perspective on identity addresses how people enact their roles in relation to others (Sluss & Ashforth, 2007). In a relational perspective, people's interactions with others also shape how people see themselves (Cross, Bacon, & Morris, 2000).

Given that chronic disease patients continuously interact with their doctors, their roles are strongly embedded in the relations with their doctors (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). Patient-doctor relations are particularly important since chronic disease patients have traditionally had to leave decisions regarding their complex conditions to doctors (Henwood, Wyatt, Hart, & Smith, 2003). Thus, the traditional role of patients has been strongly associated with their interactions with doctors. In this context, the role of doctors has been central in the provision of high-quality care (van den Broek, Boselie, & Paauwe, 2014). By contrast, chronic patients' roles have traditionally been shaped by interactions in which doctors have guided the care process. Doctors have relied on their knowledge to design the correct care and have cooperated with other healthcare professionals to provide this care. With this traditional approach, patients' roles have mostly consisted in following the advice of their doctors.

Overall, the relationship between patients and healthcare providers has long been characterized by key aspects with the following assumptions: doctor-patient interactions involve a formal process and communications (Ha & Longnecker, 2010); doctors exercise formal knowledge (Manias & Street, 2000); doctors are autonomous in decision making with limited involvement from the patient (Emanuel & Emanuel, 1992); there is high information asymmetry between doctor and patient (Peräkylä, 2006; Pilnick & Dingwall, 2011); there is a high power distance between doctors and patients (Goodyear-Smith & Buetow, 2001). Accordingly, the relationship between patients and healthcare providers has long been characterized in paternalistic terms,

with patients taking a somewhat passive role and letting their doctors be the key decision makers in their care (Giaimo, 2001).

This is particularly important for chronic disease patients whose lives and identities are significantly affected by the disease (Asbring, 2001). Upon their diagnosis, chronic patients experience significant changes in their family, social, and work lives (Tuck & Human, 1998). Chronic disease patients' identity and roles are dynamic and emergent as the chronic disease can lead patients to alter their sense of self and their relations to others (Clarke & James, 2003). Chronic diseases differ from acute conditions in this regard as they may impact patients' role and identity differently. There is a need to tackle the specificity of chronic diseases and their impact on the life of patients (Timmermans & Haas, 2008). In this respect, Macdonald et al. (2016) emphasized a lack of research on different chronic diseases and their effects on patient experiences. Chronic disease patients may differ in their use of social media, and in how their use of social media may reshape their roles depending upon the chronic disease that affects them.

4.2.2 Social media in healthcare and changing relationships

Traditionally, the negotiation of the social identity and the role of patients has occurred through face-to-face contact with others. However, recent research has indicated that social identity can also be constructed with online communications (Salimkhan, Manago, & Greenfield, 2010). Connections and social groups can be easily created online, which allows for people to give and receive feedback about themselves. Social media allow users to establish connections with others who may have similar interests, needs, or problems. People may thus continuously engage in ongoing conversations online (Ellison & Boyd, 2013). This is important in the context of healthcare as the use of social media can help patients improve their knowledge (Leimeister, Schweizer, Leimeister, & Krcmar, 2008). In this way, social media allow for the information

sharing process to shift from a traditional, formalized procedure to more unplanned connections evolving as people use social media (Faraj, Jarvenpaa, & Majchrzak, 2011).

Treem & Leonardi (2012) distinguished four key affordances, or "action potentials" associated with social media in organizations: visibility, editability, persistence, and association. These principles may also apply to a healthcare context. Patients can make their knowledge and communication visible to others (visibility). They can edit and build on each other's content (editability). Communications among patients may remain accessible even when they are not present (persistence). Patients can create connections among each other or with the content (association).

These affordances may enable chronic disease patients to reach and communicate with a large number of peers (Pagoto et al., 2014). Patients utilize social media for informal communication to get a sense of belonging and to foster relationships among one another (Colineau & Paris, 2010; Frost & Massagli, 2008). They also share emotional difficulties and encourage each other, and thus may provide each other with emotional support (Menon et al., 2014; van Uden-Kraan et al., 2008). Furthermore, with social media, patients may provide emotional support and informational support to each other (Hajli, 2014). They can exchange experiences and scientific information (Lederman et al., 2014), building knowledge about their condition and its treatments (Antheunis et al., 2013). The use of social media may help chronic disease patients to even self-manage their disease (Bauer et al., 2013; Merolli et al., 2015). Furthermore, interactions with fellow chronic disease patients can at times lead to more significant autonomy (Rasmussen, O'Connell, Dunning, & Cox, 2007).

In their use of social media, patients communicate with peers. Lederman et al. (2014) showed for instance that patients exchange information with other patients who cope with similar problems. In doing so, patients feel that they have a comparable level of knowledge about their disease and treat their peers accordingly. Hence, there is no high information asymmetry among

patients who communicate with one another. This leads to low power distance among patients; they simply share information when they believe it can help others (Anderson & Agarwal, 2011), which may increase their knowledge about the condition and potential treatments (Wicks et al., 2012). Patients can thus get empowered (Broom, 2005b; Colineau & Paris, 2010). The roles and responsibilities of doctors may also be potentially altered (Andersen et al., 2012; Overby, Slaughter, & Konsynski, 2010). This is especially important because social media may bring changes to traditional interactions and may challenge existing roles and practices in healthcare (Petrakaki, Barber, & Waring, 2012). In particular, social media may potentially enable traditionally less powerful actors (i.e., patients) to challenge others and their interactions with doctors (Agarwal et al., 2010).

Chronic disease patients may use social media and develop new roles and practices, which is consistent with earlier evidence that technology is an important trigger in developing new practices (Lawrence, Suddaby, & Leca, 2009). Through peer-to-peer exchanges of information, social media use can reinforce medical knowledge (Sandaunet, 2008), but also enable patients to address the issues that they cannot deal with in traditional settings (Schaffer et al., 2008). Thus, on the one hand, there is an established medical practice in which doctor-patient face-to-face interactions are crucial to address medical issues. On the other hand, social media afford to change relationships and connections among patients. This could lead to a variety of outcomes such as challenging doctor's authority but also strengthening the partnerships among chronic disease patients and with their doctors.

It remains unclear how social media use by chronic patients affect their roles vis-à-vis this traditional medical encounter with their doctors. The effects of social media use in healthcare still need to be investigated further (Agarwal et al., 2010; Fichman et al., 2011). Thus, we focus here on examining chronic disease patients' use of social media and its potential effects on their identity and roles vis-à-vis their interactions with other patients and doctors.

4.3 Methods

4.3.1 Research Design

This chapter aims to gain a deeper understanding of "how" the use of social media by chronic disease patients may contribute to changes in their identity and roles with regards to relationships with healthcare providers. Hence, a qualitative approach was appropriate (Maxwell, 2005). In particular, we combined netnography (Kozinets, 2010) with the interpretative case study approach (Walsham, 1995) and drew on grounded theory methods (Strauss & Corbin, 1998) to analyze and interpret data from two contrasting social media health communities.

Netnography represents a qualitative research method that adapts ethnographic research techniques to the context of computer-mediated communications and communities (Kozinets, 2010). In fact, netnography was developed precisely to study communities such as the ones emerging on social media (Kozinets, 2010) and authors in IS have applied it earlier (Campbell, Fletcher, & Greenhill, 2009; Germonprez & Hovorka, 2013). This design enabled us to examine in depth dynamics and relationships afforded by social media. However, observing online interactions in this way would not have sufficed given our interests in understanding how patients' identity and roles changed with the use of social media. Therefore, we combined netnography with a more traditional approach, namely interpretive case study approach (Walsham, 1995). This enabled us to overcome potential issues of engaging solely in an netnographic approach and of only collecting digital trace data (Costello, Mcdermott, & Wallace, 2017). In particular, this design enabled us also to get a deeper sense of patients' perspective thanks to in-depth interviews and communications with chronic disease patients from the communities we studied.

4.3.2 Research Settings

We chose two social media communities for chronic diseases. The first one is a large and well-known European online diabetes platform. We chose diabetes as it is one of the major chronic diseases. The second case is that of a small social media-based community for brain injury patients. It is noteworthy that even though brain injury is caused by an acute event such as a stroke, it then actually becomes a chronic disease (Masel & DeWitt, 2010). Furthermore, brain injury patients' daily lives and the decisions they have to make to cope with their condition are multiple, complex, changing, and personal (Eriksson & Svedlund, 2006). So, learning to cope with the condition from one another through collaborative knowledge-building could benefit patients and lead to changes in their behavior (Bodenheimer, Wagner, & Grumbach, 2002). Overall, our cases differ in size and complexity of the condition. Such paired selection of cases provided an opportunity to understand distinctions and interplay between the cases (Pettigrew, 1990). With this approach, we were able to conduct a more systematic comparison of our cases and reduce extraneous variation (Eisenhardt, 1989). Overall, our approach and selection of the cases enabled us to better address our "how" question about this complex phenomenon (Eisenhardt, 1989; Yin, 2003).

4.3.3 Data Collection and Analysis

Data collection started after the selection of the social media communities (Kozinets, 2010). The netnographic approach demanded that we join and participate in the communities to become familiar with the context and cultural aspects of the communities (Kozinets, 2010). To join the social media community for brain injury patients, we first approached a center for rehabilitation that is a part of the largest hospital in the North of Netherlands. This center had initiated a project through which a Facebook group for brain injury patients was created. The authors conducted several meetings and had email communications with the manager of the project and two coaches working on this project. This enabled us to gain insights into the history

of the project for the brain injury patients, get in touch with some of the patients, and learn how the Facebook community was initially set up. Following this, the first author joined the Facebook community in September 2014. At the same time, to gain familiarity with the diabetes case, the first author registered to the diabetes.co.uk forum. Afterward, we had contacts with the staff from diabetes.co.uk. This enabled us to observe the online content of the communities and exchange informal messages with participants to gain an understanding of the communities, which allowed us to prepare interviews and to select different interviewees.

The first author observed communication in communities from 2014 to 2017. During this period, the first author read discussions, engaged in qualitative observations of the content in the communities, and also interacted with the community members via private messages.

Moreover, we collected online data that go back to December 2013 (brain injury) and November 2008 (diabetes) by systematically downloading discussions from the two online communities. For the brain injury group, we collected all of the online communications, i.e., more than 6000 posts and comments (916 posts and 5476 comments). These discussions included text, pictures, and videos. For the diabetes group, given the large size of the group and massive volume of discussions, we relied on theoretical sampling to collect forum threads and comments. These data helped our grounded analysis and theory development (Urquhart, Lehmann, & Myers, 2010).

We scrutinized the forum threads and paid attention to the discussions that had particular theoretical resonance. For instance, in the diabetes case, we discovered a section on a high-fat low carb diet that participants referred to as having made a big difference in their condition thanks to social media use. The analysis process also led us to examine further other theoretically interesting elements such as those related to interactions between patients and doctors. Our theoretical sampling of the most revealing threads led us to examine 2741 posts resulting from 34 forum threads carefully.

In addition to these digital trace data, we conducted 21 semi-structured interviews with members of the communities from September 2014 to May 2017. Interviews were recorded and transcribed. Their length ranged from 30 minutes to 1.5 hours. Three interviews were conducted via private text messages within the community due to the reluctance of these interviewees to speak to us in person or via Skype. In some instances, during the data analysis phase, we contacted interviewees again to clarify points or pose additional questions. Interviews focused on topics associated with patient's use of social media, knowledge sharing, the meanings they ascribed to the use of social media related to their chronic disease, and the links between social media use and relations with others such as healthcare providers.

Furthermore, we had formal and informal conversations with the medical staff from the rehabilitation center (brain injury group). The first author attended informal sports events and joined lunches of the brain injury group. The first author also communicated with founders and management staff of the diabetes group. This enabled us to get a deep understanding of the context and processes at hand. Table 4.1 summarizes the collected data.

Table 4.1 Collected data

Data	**Diabetes.co.uk**	**Facebook community**
Observation of online communication	General content Content by interviewees 6392 posts and comments	General content Content by interviewees 2741 posts and comments
Semi-structured recorded interviews	7 patients and 1 doctor	13 patients
Informal contacts (including unrecorded interviews)	Messaging with other forum users Email and Skype communication with forum managers Email and forum communication with interviewees	Meetings and email communication with managers and health coaches from the Tablet program Facebook messaging with interviewees Facebook messaging with other users of the Facebook community Attending events of patients (e.g. joint lunches and sports event)
Follow up contacts	With interviewees and other forum users	With interviewees and other forum users

The data analysis process ambitioned to reveal how patients engaged with social media and how their use affected their view of themselves, their roles, and their relations with others. We relied on an iterative analysis process as we updated our interpretations and extracted new findings that were specific to social media use and to the changes that patients experienced.

To analyze our data, we started with open coding (Strauss & Corbin, 1998). Once the first codes emerged, we checked our observations with existing literature to sharpen our coding scheme and analytical gaze. Once no new code emerged from the data, we finalized the coding and switched to axial coding (Corbin & Strauss, 1990). The coding was refined throughout the process and had an iterative character as we went back to original data to refine our initial findings. We tightly linked our findings to the issues of changing identity and roles vis-à-vis others and remained open to relevant concepts and intriguing new observations. Based on the online data, formal interviews, informal communication with participants and other actors as well as observations (messages and offline encounters with interviewees), we derived our findings presented in the following section.

4.4 Findings

Our findings address how chronic disease patients' identity and roles changed due to social media use in two communities. We first present the two cases. We then examine closely how patients' identity changed and how their roles related to their relationship with doctors shifted as well.

4.4.1 Case descriptions

Diabetes.co.uk

Diabetes.co.uk was an online community dedicated to diabetes and set up by an independent third party in 2007. It offered an informative website about diabetes management and the possibility to interact with fellow diabetes patients. It has grown into Europe's largest diabetes community. The website provided health information, daily news, and information guides on

managing diabetes. Its forum included a broad network of patients with over 170 000 members. The forum featured multiple categories ranging from information for newly diagnosed patients to more specialized discussions over pregnancy with diabetes and other topics. One of the featured and very active discussion forums in this section was the one about a low-carb high-fat diet. The forum presented many individual experiences and discussions on whether, and how, a low-carb high-fat diet could help diabetes patients manage their condition.

Facebook community for brain injury patients

The Facebook community for brain injury patients was initiated by the brain injury patients who were part of a specific project from the center for rehabilitation of the largest hospital in the North of Netherlands. The objective of this project was to help patients after they had been rehabilitated and released home. Many patients still experienced problems with getting back to their normal lives. To overcome these issues, the project provided tablet computers to patients, so that they could contact their coaches at the rehabilitation center via Skype. However, next to communicating with their coaches, patients expressed concern over a lack of communication with other patients. They thus set up a closed community on Facebook with the assistance of the staff from the Tablet project at the end of 2013. Since then, the Facebook community grew to more than 300 members who are mostly former patients of the rehabilitation center.

Table 4.2 provides the summary of key observations for both cases.

Table 4.2 Summary of key observations from the two cases

	Diabetes	Facebook
Platform initiator	Set up by a third party	Set up by patients in cooperation with healthcare providers
Size	Big	Small
Degree of openness	Open	Closed
Identity of participants	Anonymous	Non-anonymous
Roles and identity of patients	Strengthening their identity and changing roles in relation to their doctors	Constructing their identity and changing their roles in relation to their doctors
Type of social media	Online community	Social networking site
Connections with others or content	Strong focus on association with the content in the community	Strong association with others in the community as well as on having a "closed and safe" place to do so. Increased offline connections
Empowerment in relation to their doctors	Silent empowerment	Open empowerment
Substitution of healthcare	Substitution of a general practitioner with experiential knowledge	Substitution of general practitioner and health coach with the convenience of finding information in social media
Building partnerships with doctors	Building partnership online with a doctor who generated changes offline	Building partnerships offline as a result of patient-to-patient online activity

4.4.2 Changes in patients' identity

From understanding to being understood and feeling connected to each other

Before joining the social media-enabled community, patients expressed a strong need to understand their condition and the situation they found themselves in. This was in particular emphasized in a brain injury group where the members were looking for the ways to "*get a grip on their situation*," as some of the patients noted:

> *"What I missed was a way to get a grip on my situation." "I just wanted to know what is the condition that I have."* (Interview from the brain injury group)

In the offline world, these patients found it difficult to understand their condition and who they were becoming as brain injury patients. They also considered that others often failed to understand them. For example, they experienced challenges with their family and doctors:

> *"…Girlfriends and husbands, wives, boyfriends, children, whatever they know how it is live with someone who has brain damage, but don't know what the brain damage is."* (Interview from the brain injury group)

The Facebook group enabled brain injury patients to establish connections with other patients as well as to feel connected and understood by the world at large. These patients exhibited a strong need to understand and feel understood. What helped in this respect was in particular feeling connected to other patients and having a small and closed social media-enabled group. These patients needed to feel that others were in a similar position and that they were not isolated with their condition. This was especially the case right after they had been released from the hospital following their rehabilitation program, as noted by this patient:

> *"When you go outside of the rehab facility, you go on your own, and you have to find out all these things. It is much easier when you have a couple of people you can ask, well, tell me how do I solve this problem than finding out it all on your own."* (Interview from the brain injury group)

Similar situations were also noted by other patients who talked about their use and need for the social media group as a way to stay connected with peers:

> *"Get in contact with people."*
>
> *"Get in contact with each other."*
>
> *"We can stay connected."*(Interviews from the brain injury group)

Furthermore, patients emphasized the importance of the size and closeness of the group, which they considered facilitated mutual understanding. In particular, patients could safely share their fears and find understanding and emotional support in other patients, as explained by one of the patients:

> *"This is very safe, and we can talk about stuff like that, and you can read stories about others and it feels comforting to me. So* [it is] *only patients, and it makes it very safe environment."* (Interview from the brain injury group)

This sense of safety also assisted patients in their understanding and becoming understood by other patients and others like doctors and family members. For example, patients emphasized

that the social media community provided them with a sense of not being just another patient "X", but, instead, of being a real, valued, and recognized individual:

> *"I would like to be a person and not just a condition."*
>
> *"I wanted to show the world that I have value and if you are patient, you can become institutionalized, and I did not want to be become* [First name], *the patient."* (Interview from the brain injury group)

Patients from this group felt that getting a real grip on their situation and finding understanding online from fellow patients also assisted them in becoming better understood by their environment. For example, they depicted situations where their doctors, family, and friends challenged them. A typical example was that of a patient who had experienced difficulties communicating with her doctors and relatives and felt misunderstood as a result. Participating in the social media group helped her to become better understood and confident as she explained:

> *"Then when I try to tell the doctor/therapist what is and what isn't working I can not get the message across and they send me home with a solution that does not work, I can feel really upset and feel like I did not explain it well. And then I can go to FB page and try to tell them the situation and the people give me support and lots of times because there are so many people in the group, right, so there is always someone who recognizes what has been going on and says wow, I was there too and I told my doctor/therapist this or that and they understood me way better and then I can use that to yea to get further along."* (Interview from the brain injury group)

These social media afforded connections however also brought new challenges, in particular in the beginning, when information posted by their peers could overwhelm some patients. For example, a patient described her initial use and beginnings as challenging regarding facing too much information and of comparing herself with others:

"For me, it was too active, too much information, all day long, so you lose track". Now I look back it was more frightening to talk than to reassure me. I got more scared. They told their story, and it was not my story because you are very vulnerable at that time." (Interview from the brain injury group)

What seemed to be rather comforting later in the process of disease management was small size of the group. This was especially clear when one of the administrators suggested a possible merger with another Facebook group to increase number of patients in the group, to which she got negative reactions:

"When I discuss something like that with the group, like let's collaborate, then people get little bit maybe scared, it's a nice group, and we already know each other. it's too big, or noooo nooo, I want to stay in this group." (Interview from the brain injury group)

Collective learning and diagnosis from experiential knowledge

Whereas their earlier efforts to diagnose and manage their disease were mostly related to their offline interactions with healthcare professionals, patients immersed themselves in collective learning and diagnosis through social media. In particular, they shared their experiences with fellow patients to help themselves and others. Patients focused on the informational and emotional aspects of their condition. For example, the following quotes from social media indicate some of the issues they discussed:

"Knowing advice when you have problems with walking, or with your arm."

"So, there are so many questions, feelings, so many that can be asked in the group."

(Interview from the brain injury group)

In particular, the patients engaged in a collective effort and appreciation of each other's advice in diagnosis, support, and assistance in the management of their condition as illustrated in this post from the Facebook group:

"I have a lot of respect for you, despite your setbacks, you fight on. Go through [Facebook group member]*!"* (From the brain injury Facebook post/comment)

Another, rather extreme, example from one of the communities revealed that a patient had self-diagnosed with assistance from fellow patients, but without consulting a doctor:

"I have not yet seen a Doctor. Basically, I am self-diagnosed diabetic, managing my blood glucose by diet and testing" (Interview from the diabetes group)

This collective effort came from a belief in the wisdom of the crowd and from having a strong connection with fellow patients who shared their condition. The wisdom of the crowd argument was perceptible as patients appreciated being able to get in touch with others who experienced their chronic disease and being able to recognize the "right" answer or direction for treatment in collected discussions as noted below:

"Knowing that there are so many other people who experience the same and knowing there is a place you can go if you have a question and the doctor does not know the answer, there are more options to get an answer." (Interview from the diabetes group)

"If someone else questions, they get ten answers, seven or eight will converge to a correct answer. One or two will be outliers. So, all you need to do is ignore the outlier and go for consensus, and you get good advice." (Interview from the diabetes group)

Furthermore, patients considered that such collective efforts produced an experiential knowledge that was more reliable than the doctor's expert, but mostly textbook-based, knowledge. A good example of this was a diet that some patients from the diabetes platform followed. This diet directly contradicted the guidelines recommended by the official medical establishment. Forum members promoted a low-carb high-fat diet as being good for the management of diabetes, even as their doctors did not endorse this diet. On the contrary, doctors promoted a low-fat high-carb diet for the management of diabetes, which, according to interviewees, did not work well for them:

"On the forum, people use a low-carb high-fat diet. The medical professionals in this country tend to say high-carb low-fat. I am not saying all of them do, I am saying that the majority do." (Interview from the diabetes group)

"*Personal experiences trumps book knowledge.*" (Interview from the diabetes group)

Similar observations were made regarding the brain injury Facebook group. Patients shared experiences related to coping with their new condition as well as associated with medicine and treatment and with the healthcare institutions that treated them. Patients viewed themselves and other patients as experts in the experience of becoming and being a brain injury patient. In a Facebook post, for instance, a patient explicitly called the Facebook-group a *"group of fellow sufferers or experience experts."* Patients gained knowledge and learned from each other's experiences:

"Yes, it is just the mutual contact. You can learn a lot from tips and experiences of others." (From the brain injury Facebook post/comment)

However, building knowledge from each other's experiences also came with challenges. This was especially related to the question of the trustworthiness of the information they received from others, especially when the information they found was conflicting and came from non-medical experts. For example, one of the patients explained his puzzlement over recommendations for dietary routines:

"Even on the forum, there are many, many conflicting reports. For instance, one may say eat bananas as a simple example. And couple days later, they say to you do not eat bananas." (Interview from the diabetes group)

"Advice being given by non-medics may be incorrect." (Interview from the brain injury group)

Other patients also worried that the knowledge they received could be coming from people who had a different health background:

"Obviously, I don't know who they are, I don't know their medical expertise, and whatever their experiences are, and similar stories may sound, their situation may still be different in a way that I don't know." (Interview from the brain injury group)

"We have to be very how do you say, selective in your information, in this group also." (Interview from the brain injury group)

Although patients showed some awareness of the risks of relying on information from people they did not know offline, they expressed a rather high level of trust in their peers as indicated by one of the patients who compared this with the information from the doctors:

"At a doctor or in the hospital there is one view, and people find that suspicious. In our community, you see a diversion of views, and paradoxically, I think these people more trust this information that the information is honest and real, you know, not necessarily totally accurate, but at least honest and without an agenda." (Interview from the diabetes group)

4.4.3 Changes in patients' roles in relation to doctors

Gaining control and getting silently empowered vis-à-vis doctors

Social media allowed diabetes and brain injury patients to build knowledge on their conditions and, therefore, to (re-)gain a sense of control in the management of their health. This constituted a notable change compared to the situation before they had joined the social media-enabled communities, as illustrated by one of the patients:

"Because before I joined the group and I would be intimidated by a doctor and frustrated with myself." (Interview from the brain injury group)

After joining and participating in the social media communities, patients developed a greater sense of control to help manage their chronic condition. Patients considered that social media use allowed them to manage their condition better and to have a stronger sense of control over it:

"SM is enabling people and make them stronger because they have so much access to information and each other." (Interview from the brain injury group)

"You manage your own health, that is how it feels to me." (Interview from the brain injury group)

Furthermore, when it came to the question of their roles in relation to others, especially doctors, the patients viewed themselves as more equal than before. In particular, they considered that their knowledge expanded and became comparable to, albeit different from, that of their general practitioners on certain aspects of their chronic condition. Patients at times asked their doctor additional questions because of what they had learned on the social media platform. They even questioned some of their doctors' care decisions. In this way, patients' role changed and challenged the traditional role of their doctors as well. Patients felt more confident and empowered in their relationship with doctors:

"The social media network gives us that confidence, then we do speak out more frequently." (Interview from the brain injury group)

With this sense of control and greater empowerment, the patients could build a more equal partnership in their relationship with their doctors, as one of the patients put it:

"We needed a new image instead of [that of a] *vulnerable patient in the blue suit and doctors in white suit. We needed a different perspective because we thought with social media we are the authority and doctor needed to follow us."* (Interview from the brain injury group)

Yet, here, an interesting difference emerged between two cases. The brain injury patients expressed their empowerment in their relation with doctors openly. By contrast, the diabetes patients seemed to do this in a subtler way, which we label as "silent empowerment".

The brain injury patients were forthcoming with their doctors about the knowledge they gained through social media and challenged their doctors directly with it. This is illustrated in the two examples below:

> *"Last time I spoke to my doctor I told him what I was, that I had the feeling that my trajectory was like I am not improving any more."* (Interview from the brain injury group)

> *"I think it makes me smarter, it gives me more information, maybe I am more difficult for the doctor now."* (Interview from the brain injury group)

On the other hand, patients in the diabetes case by and large did not exercise their feeling of empowerment openly when they met their doctors. They tended to keep silent about their social media activities, yet felt that their relationships with their doctors had become more equal. This was especially the case with regard to their relationships with their general practitioners.

When it came to the specialist doctors, this situation seemed to be different, as neither diabetes nor brain injury patients challenged the authority exercised by specialists. Patients were less empowered by their use of social media when they visited specialists than when they met with their general practitioner. Patients still highly valued the knowledge of specialists. A patient explained:

> *"I'll tell you a little secret about GP's, they are good for two things: one is to write you a prescription and the second is to refer you to a specialist doctor who knows what is going on about. With the specialist, it is much more difficult to argue or to go against."* (Interview from the diabetes group)

However, experiential knowledge building and self-diagnosing through social media use sometimes led patients to distrust doctors and the medical establishment. In particular, patients explained the benefits of low carb high-fat diet and made a difference between GPs and specialists:

"This is especially important given the medical establishment's ridiculous (in my view) insistence on a high-carb, low-fat diet, even for diabetics. anything where the diagnosis is complex, or expensive equipment or medication is needed, will still require help from medical professionals. Perhaps we will need more specialist doctors, to handle difficult diagnoses and complex medical procedures, but less generalists. A community like this can 'beat' a GP. The people here are highly motivated to spend large amounts of time and effort learning about their condition and working out how best to control it." (Interview from the diabetes group)

"On the forum, people use a low carb high-fat diet. The medical professionals in this country tend to say high carb low fat. I am not saying all of them do, I am saying that the majority do. It is certainly strong opinion coming out from the forum." (Interview from the diabetes group)

The experiential knowledge accumulation and silent empowerment patients built generated tensions with medical professionals as described by a patient in his relationship with a diabetic nurse:

"She's been trained by NHS, isn't she? But, she's been trained in local hospitals and so on. I know from other people in the forum that many diet nurses disagree entirely with what is being said on the forum." (Interview from the diabetes group)

Observations from the Facebook group also indicated differences in the relationship changes between patients and general practitioners or specialists. Regarding treatment, sharing experiences gave patients the knowledge they needed to decide to undergo a specific treatment course or not. The following post and its ensuing responses illustrate this:

"Does someone have experience with the so-called splat surgery? (in which the muscles that lift your feet are split, in order to enable you to lift your whole foot more easily?)" (From the brain injury Facebook post/comment)

Multiple reactions followed, and one comment illustrated how shared knowledge was used in decision making:

"Partially because of your experiences I decided to have this surgery done! I have had nice consults with Dr. [Last name] *in the MCL. I have a lot of faith in this treatment."* (From the brain injury Facebook post/comment)

All in all, patients developed a perception that their general practitioners were not up to date on all medical knowledge and treatments. This motivated them to share experiences with peers via social media. They then used this knowledge to make decisions on specific medicines and treatments. Knowledge sharing regarding medication was for a large part based on experiences from peers. In this way, patients somewhat bypassed general practitioners but did not question specialists' knowledge.

It is noteworthy that not all encounters with general practitioners were positive as a result of this newfound empowerment. A brain injury patient who had visited her general practitioner and company insurance doctor and shared with them some information she had accessed via social media use explained:

"I think they [the doctors] *kind of felt like I was trying to undermine their authority, that was not of course what I was going for, I just read stuff that sounded relevant to me, and I wanted their opinion on it. I didn't mean to take their advice and ignore."* (Interview from the brain injury group)

Substituting vs. complementing offline healthcare provision

Social media use sometimes replaced the healthcare provision patients received from their doctors. In particular, patients relied on each other to answer multiple questions on how to manage the various aspects of their condition. As they did this, patients did not need to visit their doctor as much. Moreover, when they went for a doctor visit, they at times mostly sought to confirm what they were already thinking and doing with the help of their fellow patients online. However, again, this dynamic was more evident in the relationship between patients and general practitioners rather than with specialists. For general practitioners, this substitution of offline healthcare provision with social media was more complete than for specialists.

For example, patients from the diabetes platform still went biannually to their regular check-ups. However, they tended to resolve many of their health issues with social media use, in particular as these issues related to their diet. Patients relied heavily on social media knowledge obtained through the experiences and advice of peers. They discussed dietary concerns in much detail and looked through the forum for information. Moreover, patients usually did not use official online sources for information about their condition. Instead, patients trusted the knowledge they built with peers through social media. The following quote illustrates how the roles of the doctor and the patient changed and how the provision of healthcare evolved:

> *"My relationship at the moment is that I am following the conclusions that I come to myself with the advice from the forum and I just go and see my diet nurse every six months to confirm that everything is as it should be. In other words, she is at the end of the process rather than at the begging. It should not be that way, I know, but it is."* (Interview from the diabetes group)

This finding also revealed some interesting differences between two of our cases. When they substituted for healthcare provision, brain injury patients did it mostly for the sake of convenience. They considered that going to doctors and explaining their situation required an

effort whereas the issue could be conveniently resolved with the help of other fellow patients online. They asked their questions in the Facebook group and hoped to resolve the issue in this way:

> *"For me, it is easier to ask on SM than to call the hospital."* (Interview from the brain injury group)

This choice was particularly prevalent among brain injury patients for any issue that did not cause too much trouble regarding pain or discomfort as one of the patients explained:

> *"I go to social media, but when I have issues like my foot is hurting and I do not know what is going on for few weeks, then I go to the doctor."* (Interview from the brain injury group)

On the other hand, diabetes patients emphasized their strong feeling of trust in their fellow patients in the community. They considered that sharing the same chronic condition on social media while general practitioners did not make online interactions more relevant and trustworthy than those with doctors. Diabetic patients therefore heavily relied upon advice put forward on social media by fellow patients. This is best illustrated by one of the patients who decided to follow the low-carb diet as a cure for her problems instead of taking the medications prescribed by her doctor:

> *"I used it at that stage for that, to ask a question and was given replies. And that changed my life basically, completely changed my life. So, I did as it was suggested and everything changed, I am off the medication, and I am well." "My GP, doctor here did not believe that I control my Diabetes. She said you will definitely need medications. There is absolutely no way you will be not needing medications, and I don't. My levels are under diabetic now, so."* (Interview from the diabetes group)

To explain why she followed advice from social media rather than from her doctor, this patient emphasized that her fellow patients suffered from the same condition while her doctor did not:

"Because it was recommended by the people with diabetes, and it had worked for them. So, that's why. GPs, you know, they don't have the illness, and they do not feel it." (Interview from the diabetes group)

This substitution in the origin of care did not fully negate but instead deeply transformed the required expertise of doctors and relevance of the patient-doctor relationship:

"I think it [social media] *already replaces it* [visiting doctors] *for first for like maybe 80%. It does not mean that the leftover of 20% is not important. Maybe it is the most important, but 80% is more reassurance, emotional reassurance or questions, and Facebook or the people you know through Facebook, they can already replace in all the knowledge they have."* (Interview from the brain injury group)

Furthermore, another patient emphasized the importance of going to see a specialist when they worried about a serious issue:

"We all have experiences with things, but we are not specialists. When I have real issues with my body, I would go to a doctor." (Interview from the brain injury group)

Hence, patients' increasing knowledge and substitution of certain parts of healthcare with social media use did not fully rule out the need for specialists' expertise and care:

"Together we have much more knowledge than one doctor has I think. But I do not think that the [social media] *group can replace doctors or therapists because of our* [interactions can be] *colour* [ed] *by emotions and irrational thoughts."* (Interview from the brain injury group)

Furthermore, patients saw the constant use of social media and the on-going but a more occasional visit to specialists as complements rather than substitutes:

"Doctors look always look on the medical side of it and not as much as the personal side. The group like this is more about the person. So, I think that is big difference. It is an addition, it is not a replacement." (Interview from the brain injury group)

Emerging new collaborations and partnerships with doctors

Social media use enabled patients to establish new forms of collaboration and partnership with doctors leading to changes in the provision of their healthcare. We observed such changes appearing in both cases, albeit in slightly different ways.

The brain injury patients increased their use of online resources as they communicated via the application WhatsApp, which then eventually resulted in increasing their offline interactions as well. In their Facebook group, brain injury patients had met and often exchanged their cell phone numbers. They then created a WhatsApp group to stay in touch and to be able to contact each other at all times. This also led them to meet with one another offline. One of the challenges they identified in their dealing with their new chronic condition was their missing being able to exercise. As they became aware of their shared desire to start exercising again, brain injury patients asked the manager and rehabilitation coaches at the rehabilitation center to help them implement an exercise program. Such initiative eventually led them to form a joint sports group. As an outcome of this, the rehabilitation center hired a new employee and introduced the concept of training with a sports coach who now worked with these patients on a weekly basis. The sports group brought patients together with the sports coach from the rehabilitation center. Patients regularly met to exercise together and felt better connected to each other as a result. In large part triggered by an initial WhatsApp conversation, brain injury patients had initiated a change in their relationship with their healthcare providers, which led to the creation of a new healthcare role of a sports coach. Patients also formed a new type of relationship with some of their health coaches who joined them on social media and their offline meetings. A patient explained:

> *"After the meeting in* [Rehabilitation center name]*, FB was started, and they invited to join, invited me to join them. I joined, and we got in contact with each other, and then the sports group started, it was first FB group in December 2013 it started, or I became a member. I*

think in March 2014; the sports group started, that's kind of timeline." (Interview from the brain injury group)

There was another situation in which such use of social media did not lead to new partnerships with doctors, but, rather, to new patient partnerships that aimed at helping patients and others on a larger scale. One of the brain injury patients started an online initiative with another patient whom he had met via social media. They created a resource to help patients and others meet one another and find people who could act as informal caregivers:

"[Website name] *is a marketplace where everybody in Holland can join for free, login with an email address or Facebook account, and then you come in contact with people. Finding each other, walking do with each other and go visit the concert or having dinner together."* (Interview from the brain injury group)

The brain injury patients, therefore, used social media to form new relationships and partnerships that also eventually translated offline.

Changes also appeared for diabetes patients who used social media to form new partnerships with doctors online, which led to further offline changes. More specifically, diabetes patients promoted and built knowledge related to the low-carb diet on social media. As detailed supra, diabetes patients remained somewhat silent on this with their regular doctors and healthcare providers. However, a few doctors were members of the online forum. Diabetes patients interacted with them. A good example of a new partnership formed online between diabetes patients and doctors related to a general practitioner who had joined the forum because one of his patients had successfully tried the low-carb diet and been able to manage his condition fully via the dietary change. As this doctor joined the community, patients at first viewed him as a "troll" and enemy of the community. Patients did not believe in his medical credentials. Yet, with persistence, this doctor slowly started to gain the respect in the online community. After having learned about practical effects of the low-carb diet and its benefits for diabetic patients,

he then organized a controlled trial, which exposed more patients to the low-carb diet. The results of this study were encouraging and further indicated that the low-carb diet worked efficiently for patients. The doctor also published a scientific article showing the benefits of the diet and called for more changes in the attitude of healthcare professionals in valuing patients' experiential knowledge and use of social media. As reported on diabetes.co.uk:

> *"Dr.* [Last name]*, who shared his findings on the Diabetes.co.uk forum concluded: "The patient steadily lost a total of 16 kg over seven months and successfully stopped all four prescribed drugs, thereby achieving his goal of being medication-free. This was accomplished using a low carbohydrate diet—in his words: 'more a lifestyle than a diet."*
> (From the diabetes community post/comment)

Overall then, using social media enabled chronic disease patients to adjust the way they viewed themselves, to exchange with one another, to curate experiential knowledge, and to change their role and some of their relations with doctors.

4.5 Discussion

The objective of this chapter was to examine how social media use by chronic disease patients affords changes in their identity and roles in relation to healthcare providers. To do so, we drew on a social identity perspective with an explicit interest in the relational aspect of chronic disease patients' identity and roles in the context of social media use. Our findings revealed how, with social media use, chronic disease patients may get connected to each other, engage in collective learning and diagnosis, become empowered in their relations with doctors, substitute or complement their healthcare provision, and construct new types of collaboration and partnerships with doctors.

First, chronic disease patients in both communities strongly connected to one another and the online communities as they used social media. This is not surprising per se, given that earlier

studies have shown that patients use social media to provide each other with social support (Bugshan, Hajli, Lin, Featherman, & Cohen, 2014). In our cases, patients focused on informational and emotional support as two components of social support (Schaefer et al., 1981). We also observed differences between the two cases that relate to the social media affordance of association. This affordance enables social media users to create and sustain connections among one another or with the content (Treem & Leonardi, 2012). In the case of brain injury patients, interpersonal connections were highly emphasized, which even led to additional offline contacts among patients. By contrast, the diabetes case did not show a strong association between patients, but rather between patients and the content of the online platform. This was also related to the social media affordance of visibility, which made patients' knowledge and communication visible to others. The brain injury patients favored limited visibility as a closed group, which shaped the way in which patients communicated on social media. On the other hand, diabetes patients had a broader and more open community where non-registered users could also see posts, which further actualized the affordance of visibility. These differences between the cases suggest how social media use and subsequent outcomes may differ somewhat depending on the type of chronic diseases and the online context at hand. In other words, the type of chronic disease and type of social media platforms may affect how patients develop their identity and exercise their roles. This points to the interplay between technology and human actors (Bélanger, Cefaratti, Carte, & Markham, 2014) and highlights the complexity of chronic diseases, which is consistent with expectations of Macdonald et al. (2016).

A second key finding came from the observation that patients from both communities engaged in the process of collective learning and in diagnosing themselves from layman knowledge. Consistent with previous research (Majchrzak, Wagner, & Yates, 2013), we observed a conversational model of knowledge sharing as many chronic disease patients made small

contributions to the online conversations. Although patients shared knowledge also by posting external links and personal experiences, they mostly did so by disclosing their experiences. As Kirchner et al. (2009) argue, collective knowledge sharing happens simultaneously with personal knowledge management. We could recognize in our cases patients collaborating around information, analyzing information and presenting as well as refining knowledge. Yet, an interesting departure in our cases from extant literature was that the patients did not engage in evaluating knowledge or in assessing systematically its quality and relevance, which was suggested as important in Kirchner et al. (2009). A plausible explanation for this was that assessing the quality and relevance of the knowledge was far from a straightforward task in social media-afforded health communities. This was, in particular, the case because patients did not know each other very well and because many participants made small contributions to the online knowledge base.

A third key finding from the cases was that chronic disease patients became empowered in their interactions with doctors thanks to their use of social media. Early research on the use of online health resources had suggested that it empowers patients in relation to their doctors (Broom, 2005b). Furthermore, earlier research has shown that patients clearly communicate the empowerment to their healthcare providers (Bartlett & Coulson, 2011) and that such situation also applies to chronic diseases such as diabetes (Funnell & Anderson, 2004). Our findings allow us to question this existing scholarship further because our findings indicated a distinction between two types of empowerment for chronic disease patients. On the one hand, social media use allows patients to challenge their doctors openly, as suggested by the extant literature. On the other hand, and so far, unexplored in existing scholarship, social media use may also enable patients to feel empowered while remaining silent about their empowerment in their dealings with doctors. Hence, an intriguing finding of this chapter is that some chronic disease patients who become silently empowered with their use of social media may not appear to have changed

(e.g. their check-ups with doctors unfold as they traditionally did). Yet, the identity and role of these silently empowered chronic disease patients have changed.

With regards to the effect of social media use vis-à-vis substituting or complementing healthcare provision from their doctors, the cases revealed that chronic disease patients may decrease their interactions with doctors and rely on the self-management of their condition (Bauer et al., 2013; Merolli et al., 2015). New behaviors associated with social media use amongst chronic disease patients challenge the traditional role of doctors as dominant and leading actors in the healthcare process. Although there seems to be a trend in decreasing interactions with doctors from social media use, our findings showed that patients still interacted with doctors, especially in prescribed periodic check-ups.

The same applies to differences between generalist and specialized knowledge. The knowledge of general practitioners was more readily replaced with social media use than specialists' knowledge, which remained mostly unchanged. Furthermore, the cases revealed how chronic disease patients could substitute using social media for meeting their general practitioners. At the same time, the new role that the chronic disease patients took changed and complemented, rather than substituted for, interactions with specialists. For treatment of their chronic condition, patients who use social media take a new proactive role in the relationship with general practitioners. However, they remain in a more passive yet changing role in their relationship with specialists. More generally, then, the use of social media does not affect chronic disease patients' identity and role with regard to key healthcare providers in a uniform manner.

We also found, intriguingly, that social media use by chronic disease patients led to the emergence of new partnerships with doctors. We identified several changes in the interplays between the roles of patients and doctors. In particular, we noted the importance of types of actors as well as of social media in shaping the interplay among actors (Smink, Negro, Niesten, & Hekkert, 2015). While social media played an essential role in enabling patients to develop

a different role, we saw that, as chronic disease patients developed a new role for themselves, the roles of some doctors could be affected as well. In particular, social media use enabled chronic disease patients to establish new partnerships and to influence the behavior of doctors and other healthcare providers. This was evidenced in the example of the brain injury platform that initiated a sports group that led to the creation of the new function of a sports coach. In this way, social media use enabled traditionally less powerful actors (i.e., brain injury patients) to bring about a change in the way their rehabilitation program took place. In other words, chronic disease patients who use social media can adopt new roles, change their behavior, and bring about further changes in their interactions with doctors and healthcare providers.

4.5.1 Theoretical Implications

This chapter adds to the understanding of the emerging phenomena of digital initiatives in healthcare, particularly in the context of the management of chronic diseases. Our findings bear implications for scholarship on HIT, on the relationship between patients and healthcare providers, and on the role of social media use on the construction of identity for chronic disease patients.

First, this chapter extends the HIT literature. Most of the existing scholarship has focused on topics such as privacy concerns, interoperability and resistance to change (e.g., Romanow et al. 2012). We add to this literature by studying how new technology such as social media may affect patients and their relations with doctors. In this way, we also take on the patients' perspective, which adds to the earlier literature in this field that had paid limited attention to such perspective, as noted in Agarwal et al. (2010). Moreover, only a few studies focused on the patient's perspective and patient-centered applications beyond electronic health records (Goldzweig, Towfigh, Maglione, & Shekelle, 2009). Findings of this chapter add to this literature by exploring the effects of social media on the relationship between patients and healthcare providers, which IS researchers have called for (Agarwal et al., 2010; Fichman et

al., 2011). This chapter starts filling this research gap. It also further elaborates on this aspect as it relates to the relationship between patients and healthcare providers in chronic disease management.

Second, the traditional relationship between patients and healthcare providers has been characterized by information asymmetry and the power imbalance between doctor and patient. A more significant focus on patient-centered approaches and the use of online health resources has, to a certain extent, empowered patients (Bartlett & Coulson, 2011; Mano, 2014). However, doctor-patient interactions have still by and large been characterized by high information asymmetry (Pilnick & Dingwall, 2011). Existing studies suggested that the use of social media by patients might challenge the traditional relationship between patients and healthcare providers regarding empowerment (Colineau & Paris, 2010). The most crucial task for doctors in this traditional relationship was to provide patients with objective medical information, known as "technical" tasks (McMullan, 2006). However, our findings show that, with social media use, chronic disease patients build and rely on informal knowledge to manage their condition, which eventually leads to changes in their interactions with doctors. In particular, patients in the two investigated communities have become more technically informed patients. Extant literature had focused on changes in power and authority between doctors and patients. Van Uden-Kraan et al. (2010) showed for instance that the use of social media by patients threatened and challenged doctors' authority. Relatedly, Broom (2005) argued that patients' use of social media created new power imbalances between doctors and patients.

This chapter further builds on this existing scholarship. It found, indeed, that chronic disease patients' use of social media had diminished the "leading" role of doctors. However, and more precisely, the use of social media by patients led to new relationships and partnerships with doctors. An important implication here is a clear and intriguing difference between general practitioners and specialists in several aspects. While the authority and knowledge of general

practitioners faded in the eyes of diabetes and brain injury patients, specialists' authority and knowledge remained somewhat untouched. This finding could be generalizable to other professions outside of healthcare, suggesting that the knowledge and authority of specialist professions may remain stable and valued whereas the generalists could be substituted as social media makes more experiential knowledge available.

In terms of healthcare management, our findings are somewhat consistent with Hwang and Christensen's (2008) suggestion that business models in healthcare will eventually change in that the specialist knowledge on managing chronic diseases will be transferred to patients themselves, thus reducing the importance of generalists in managing chronic diseases. Overall, this chapter in this respect focused on the micro-level of patient's roles and their doctor-patient interactions. The changes in their roles highlight the importance of micro-level interactions among patients. Furthermore, changes in their role also affect existing and enabling new practices in behaviors with doctors. This chapter also reveals that these changes in practices may lead to the emergence of new practices at broader levels of analysis as suggested by Smets et al. (2012).

Third, our findings bear implications for studies of chronic diseases regarding their impact on patient identities and of how social media use may interfere with these identities. In particular, we add to the understanding of how patients construct and re-construct their identity regarding their specific disease in the interplay with social media use. Extant literature often views chronic diseases uniformly. Yet, the specificity of the disease could play an important role in the management of the disease (Jabbour et al., 2010) as well in how the lives of chronic disease patients are affected (Macdonald et al., 2016). In our particular cases, we observed a difference between two chronic diseases, namely brain injury and diabetes. On the one hand, brain injury patients were constructing their identities in terms of who they were and what they did vis-à-vis others, given that their injury was still recent. On the other hand, diabetes patients had

typically long been diabetic. Therefore, they were in the process of re-constructing an already established identity. This chapter thus challenges the somewhat uniform view of chronic diseases and identities of chronic disease patients (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Lorig & Holman, 2003), especially in regards to the impact of new technologies on the lives and identity of chronic disease patients. In this respect, earlier studies focused either mostly on single chronic disease (Høybye et al., 2010; Klemm, Craddock, & Preece, 2012; McLaughlin et al., 2012). Our findings indicate differences with regards to how social media use may affect the construction and reconstruction of patients' identities. Specifically, the affordances of visibility and association played a crucial and very specific role in enabling the emerging construction versus re-construction of the identity. This is in line with the idea that the identity of chronic disease patients can change (Clarke & James, 2003). In particular, chronic disease patients' identity may depend on their specific disease as well as their use of social media.

4.5.2 Practical Implications

Practical implications of this chapter concern chronic disease patients, healthcare providers, and policymakers. In particular, chronic disease patients could understand better how their use of social media for health-related purposes may lead them to apprehend their situation differently and to undertake new roles in the management of their disease. Healthcare providers could also get a deeper sense of how the use of social media by patients may have an impact on the healthcare provision process. Healthcare providers could adapt to address better patients' changing needs and demands. Moreover, they could gain insights into how they may become involved in online communications and potentially assess patients' experiential knowledge and bottom-up treatments. Healthcare policymakers may use findings from this chapter to promote the use of social media, and to follow closely ongoing changes in the relations between doctors

and chronic disease patients. However, the health policymakers should also consider that consequences of potential substitution of healthcare provision via social media.

4.5.3 Future research

We note that our research has limitations that constitute promising opportunities for future research. In particular, we studied two social media health communities for two different chronic diseases. We also noted some differences between the cases regarding the emergence of the new roles and effects on doctor-patient interactions. We do not claim empirical generalizability for our qualitative findings, but, rather theoretical generalizability (Lee & Baskerville, 2003). We thus call for further research to assess further and test our findings, perhaps in a quantitative way, with a larger sample. Furthermore, this chapter took the patients' perspective and focused on micro-level doctor-patient interactions. Future research could focus on the doctors' perspective as well. It could thus explore how interactions change from the doctors' perspective and how chronic disease patients' new roles affect the wider context and other actors in healthcare. Patients' learning from others could affect patients' sense of self-efficacy and health motivation. Thus, it could be interesting to study such changes further, especially given recent calls to examine the processes of how knowledge sharing in social media health communities lead to an increase in quality of life and health-outcomes (Fernández-Luque & Bau, 2015; Househ, Borycki, & Kushniruk, 2014).

Chapter 5: Changing roles of doctors through technology use of patients: an occupational identity perspective[4]

Abstract

This chapter examines how roles of doctors change as a result of their patients' use of social media. By drawing on occupational identity theory, we contribute by demonstrating that technology use of clients can affect roles and identities of professionals. Traditional roles of doctors were focused on their authority and guiding patients. However, new technologies like social media are challenging this traditional relationship between patients and doctors. We conducted semi-structured interviews with doctors to explore how they respond to the social media use by their patients. Our findings show that the roles of doctors are changing. In particular, we show that doctors learn from their patients and they focus more on soft and social-emotional aspects of the relationship between patients and healthcare providers. As a result, their roles change in the sense that they become less focused on authority and technical tasks. With this chapter, we contribute to the stream of literature on health information technology and occupational identity by identifying how new technologies such as social media change roles of doctors indirectly. Furthermore, we enrich occupational identity literature by showing the indirect effect of new technologies on "what we do" aspect of occupational identity.

[4] This chapter was written together with Albert Boonstra and David Langley. A previous version of this chapter was presented at the workshop of International Conference on Information Systems (2016).

5.1 Introduction

Professionals have always had a significant role and enjoyed a high level of autonomy in the society (Larson, 1977). This is particularly the case in healthcare where the research on roles of doctors has attracted significant research attention (Goodrick & Reay, 2010, 2011; Pratt et al., 2006). In healthcare, roles of doctors as professionals can occur in two ways. This takes place through taking an oath and proclaiming a public commitment to the profession of a doctor and through daily interactions with other actors in healthcare (Pellegrino, 2002). In this chapter, we focus on the interactions with patients, which is the core of the doctors' work (Gottschalk & Flocke, 2005).

In the relationship with their patients, doctors have an essential role in deciding on the appropriate care. In doing so, they exercise formal process and communication with their patients (Ha & Longnecker, 2010). Earlier studies have revealed that the roles of doctors are autonomous and they are key decision makers in the traditional relationship with patients (Colineau & Paris, 2010; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Peräkylä, 2006). In the relationship with the patients, they rely on their formal knowledge and take a high-power distance towards patients (Goodyear-Smith & Buetow, 2001). This approach results in high information asymmetry between them and their patients (Pilnick & Dingwall, 2011). In summary, doctors possess a unique set of skills and knowledge. Thus they are often given a central role and authority in providing medical advice (Offenbeek et al., 2012).

By occupational identity, we refer to a connection between occupation and individuals' personal and social identity. Practicing a certain occupation contributes to one's construction of identity, and it also represents a primary way to show one's identity (Christiansen & Bryan, 1999). Kielhofner (2002) defined occupational identity as a sense of whom one is as one's participation in a particular occupation through practicing and experiencing that occupation. In

particular, the literature on occupational identity deals with two aspects of identity, namely "who we are" and "what we do" (Ashcraft, 2013; Nelson & Irwin, 2014; Pratt et al., 2006). This chapter focuses on how the use of technology by patients is changing the occupational identity of doctors, especially regarding "what we do". The extant literature on occupational identity and technology has mostly focused on the aspect of "who we are". Thus, the scholars have offered less attention to the question "what we do" (Nelson & Irwin, 2014). In their recent study, Nelson and Irwin (2014) show how the occupational identities of librarians who interact with new technology change "what they do". For example, librarians used to see themselves as masters of searching, but due to the Internet, they shifted to more of seeing themselves as the ones who interpret the results and manage things such as organizing collections of resources. Even earlier studies have also shown that technologies can affect occupational identity. For example, Leonardi (2007) indicate how roles of IT technicians changed as a result of interactions with the technology. Furthermore, Mishra et al. (2012) explore how the identity of doctors change in the light of introducing electronic healthcare systems. Overall, this stream of literature shows how individuals interact with technologies, which ultimately has an impact on their occupational identity.

However, the core of how occupational identities are shaped does not lie in individual interactions with the technology itself. Identities are relational and strongly embedded in interactions (Vough et al., 2013). Thus, roles and identities are enacted vis-à-vis others through interactions (Langley et al., 2012). This is also the case in healthcare where the identity of doctors gets shaped in interactions with different actors (Reay et al., 2017). For example, Reay et al. (2006) showed that the changes in roles of nurse practitioners included interactions with other health professionals. Although the concept of occupational identity and in particular the question of "what we do" is strongly relational and embedded in interactions with others, extant literature has somewhat ignored this (Reay et al., 2017).

In healthcare and with doctors, in particular, the traditional role or the question of "what we do," vis-a-vis the relationship between patients and doctors is challenged by the patients' increasing use of new technologies such as social media (Colineau & Paris, 2010). In particular, the use of social media by patients is starting to challenge the traditional role of doctors (ibid). With the social media, patients have more access to medical information (Gómez-Zúñiga, 2012). Access to medical information from social media improves patient's understanding of health-related issues and influences their treatment decisions (Antheunis et al., 2013). This may create patients who are no longer satisfied with the traditional roles of their doctors (McMullan, 2006). More precisely, the patients increasingly use medical information that they retrieved from social media in their interactions with doctors (Van Uden-Kraan et al., 2010). Hence, the roles of doctors seem challenged by increasing use of social media by patients. Thus, in this chapter, we explore how doctors respond to social media use by patients and how their identity changes in terms of "what we do".

In addressing this issue and linking the literature on the role of technology and occupational identities, we focus our efforts on exploring the change in the role of doctors through their interactions with patients who use social media. Thus, we focus on the indirect effect of technology. In other words, we explore how the use of social media by patients affects the roles of doctors in relation to their patients. Accordingly, we address the research question: *How does the occupational identity of doctors in terms of "what we do" change as a result of social media use by patients?*

This chapter has a two-fold contribution. First, it adds to occupational identity literature by extending the literature on how technology affects the "what we do" of occupational identity. In particular, we account for the indirect effect of technology, specifically interactions, which has been somewhat neglected earlier (Reay et al., 2017). Second, we contribute to the healthcare

information technology stream of literature. In particular, we contribute to this stream of literature by deepening our understanding of the changes in roles of doctors due to social media use of their patients.

5.2 Theoretical background

5.2.1 Occupational identity

Identity refers to the meanings, which define an occupation in terms of being a person, role occupant or member of a certain group (Nach & Lejeune, 2010). Thus, the identity elaborates on who one is and answers the question of "Who am I?". In regards to occupational identity, it comes down to two aspects of identity, namely "who we are" and "what we do" as members of certain occupation (Ashcraft, 2013; Nelson & Irwin, 2014). Hence, occupational identity extends the concept of identity to the part of "what we do". To construct and keep their identity, occupational members use different rhetorical and narrative means in differentiating themselves and their occupation (Ashcraft, 2007). In doing so, they continuously negotiate roles and duties that are part of a particular occupation regarding the meanings that the members relate to these roles and duties. This implies that occupational identities are not static and they change over time. They indeed are temporary in that one's life, and occupational identity is continually being redefined in incremental and occasionally in disruptive ways (Ibarra, 1999).

For example, Ashcraft (2007) shows the process in which professional pilots engage as they face the threat of "crew empowerment policy" with regards to their identity. Furthermore, another study by Obodaru (2017) shows how people deal with their foregone identities. In particular, she focuses on how people keep their forgone identities and sometimes enact them in their self-concept. These studies focus on the "who we are" concept of the occupational identity. Scholars have so far paid less attention to the aspect of "what we do" (Nelson & Irwin, 2014). According to Ashcraft (2013), "what we do" truly represents the actions and identity of

occupations. Hence, it is important to get a better understanding of changes in what members of occupation do. Otherwise, it is hard to understand occupational identity in itself. Indeed, as Sluss and Ashforth (2007) put it, enactment of particular roles in terms of values, norms and interactions styles give the role identity.

The aspect of "what we do" is powerful for professionals. For example, Pratt et al. (2006) show that professionals tend to explain how they see themselves in terms of what they do. In particular, they describe what they do and distinguish themselves from other occupations. Many of these studies focused on how education and training affect roles of professionals (Reay et al., 2017). Furthermore, earlier extant literature was focused on how people define and see themselves in organizations. Overall, this approach has strongly emphasized building individual identity vis-à-vis their collective and thus ignored the interpersonal levels between members of their organization. However, the relationships with others within the organization affects one's identity in what Sluss & Ashforth (2007) relate to as relational identity.

This implies that identities are strongly embedded in interactions (Vough et al., 2013). In other words, the identities are relational and are shaped regarding how one relates to others. In particular, professionals such as doctors engage in defining their occupational identity by relating themselves to others, which takes place through their interactions (Real, Bramson, & Poole, 2009). Thus, occupational identity is not just the perception of the occupational member about himself, but a number of activities and interactions that provide sense about himself and his identity (Brocklehurst, 2001).

Whereas most studies take this strong assumption, they somewhat overlook the role of interactions in this process of redefining identity, especially regarding roles (Reay et al., 2017). We argue that this is particularly the case in studies of technology and occupational identity, which we elaborate on in the next section.

5.2.2 Identity and technology

With the rise of information technologies (IT), there has been increasing impact of IT on the way people work (Cascio & Montealegre, 2016; Walsham, 1998). In particular, IT may be changing the way they perform their roles (Lamb & Davidson, 2005). The studies in this field have covered a wide range of topics. For example, Trauth (2002) explored the link between IT and gender identity. Mosse and Byrne (2005) have shown how the implementation of information systems and building identity are interrelated. These studies also cover the role of technology and its impact on occupational identities. So far, some studies have shown that technologies affect occupational identity and vice versa (Lamb & Davidson, 2005; Leonardi, 2007; Leonardi & Barley, 2010; Nelson & Irwin, 2014; Orlikowski & Scott, 2014; Walsham, 1998). Early work of Walsham (1998) has explored the work of professionals in the financial and pharmaceutical sector in relation to their identity through the use of IT. Lamb and Davidson (2005) extended their work to include the role of technology in the context of scientists not just observing what identity is, but also how it evolves through the use of IT for collaboration. Moreover, Nelson and Irwin (2014) show how the internet redefined the work of librarians and how their occupational identity changed. However, Nelson and Irwin (2014) also noted that the extant literature has not fully explored how occupational identities interact with technology. Furthermore, the studies in this stream of literature mostly focus on the direct effects of technology on occupational identities and interactions of the professionals with technology. Yet, extant literature strongly suggests that identities are relational and embedded in interactions. However, at the same time, the explicit attention on interactions and their contribution to shaping identity is still lacking. This is, in particular, the case for changing identities of professionals who engage in interactions with other actors who are using technology. In other words, this represents an indirect effect of technology on occupational identity. A recent study by Sergeeva, Huysman, Soekijad, and Hooff (2017) looks at the role of

onlookers (i.e. actors who do not directly use the technology, but for whom the use of technology is visible) and how they affect the use of technology. In a similar line of thought, we are exploring this issue in occupational identities to go beyond the user-centric perspective on technology and occupational identity.

5.2.3 Occupational identity of doctors

As a profession, doctors have always enjoyed prestige, such as professions, headmasters, and lawyers. While to a certain extent healthcare is a unique context, it is also similar to other professions like, for example, education or law or accounting (Nelson & Trubek 1992; Hinings et al., 1999). Earlier literature has usually focused on the identity of doctors and nurses (Sehested, 2002). Doctors build their occupational identity on their personal identities that they develop during their life (Monrouxe, 2010). As such, they can be influenced by their friends, families, colleagues and other external factors (Jarvis-Selinger, Pratt, & Regehr, 2012). They are also subject to the influences of the culture and the environment they join. Actually, they fully form their occupational identity when they enter the medical field (Cruess & Cruess, 1997). In this sense, doctor's identities are strongly shaped by their formal education and knowledge (Freidson, 2001). This results in situations where doctors see themselves as central actors in healthcare and exercise a high level of autonomy (van den Broek et al., 2014). In line with this, previous studies have also shown that doctors resist the change and often reject to adapt their roles and what they do (Currie, Lockett, Finn, Martin, & Waring, 2012).

However, this is not always the case. For example, Goodrick and Reay (2010) studied how nurses legitimize their occupational identity in education through a slow process of adopting new arguments, which do not delegitimize their past practices. This points to how the work of medical professionals gets challenged by different forces, such as the introduction of new curriculums. The same applies to other forces like economic and organizational factors, which eventually have an impact on how medical professionals see themselves and shape their identity

(Pratt et al., 2006). However, these studies also conclude that the interactions may play an important role in shaping occupational identity (Goodrick & Reay, 2010). In the same line, Reay et al. (2006) emphasized the importance of interactions with others in the process of adopting their new roles. This is especially the case for interactions with patients (Teal & Street, 2009). For example, Pedersen (2008) shows how the identity of rehabilitation professionals was shaped through the interactions with their patients and colleagues. Interactions with patients are one of the most important aspects of doctor's work (Gottschalk & Flocke, 2005). However, this aspect has not received much research attention (Reay et al., 2017).

The issue of shaping their occupational identity through interactions with patients becomes even more pronounced with recent technological developments. In particular, the emergence of the Internet technology and social media has brought about a change in healthcare as it enabled patients to look online for health-related information. In particular, the use of social media by patients is starting to challenge the traditional role of doctors and the relationship between patients and healthcare providers (Colineau & Paris, 2010). With the social media, patients have more access to medical information (Gómez-Zúñiga, 2012). In particular, access to medical information from social media improves patient's understanding of health-related issues and influences their treatment decisions (Antheunis et al., 2013). As a result, patients have extensive access and availability to medical information. This may create patients who are no longer satisfied with the traditional roles of their doctors (McMullan, 2006). This means that patients want to be fully informed and have more influence on the overall decision-making process (ibid). Hence, the roles of patients seem to possibly shift from passive actors to more active actors in their relationship with doctors and this, in turn, has an effect on the role of the doctors. However, as illustrated in our literature review, we still lack understanding on how roles of doctors change through the social media use of their patients. In this chapter, we aim to deepen our understanding of this change, thus contributing to the literature on occupational identity and

health information technologies. In particular, we aim to deepen our understanding of the indirect effect of technology on the occupational identity of doctors and focus on their roles, hence the aspect of "what we do".

5.3 Methods

5.3.1 Research design

Since there is not much theoretical background for a deductive approach to this topic, we used a qualitative approach to provide new insights into the changes of doctors' occupational identity in terms of "what they do" (Eisenhardt, 1989; Yin, 2003). Furthermore, our research question aims to explore phenomena which are poorly understood as we raise the question of "how". Hence, qualitative research is indeed considered to be an appropriate approach (Maxwell, 2005; Yin, 2009). In our research, we particularly focus on how the "what we do" part of occupational identity changes as the result of the social media use by their patients. In other words, we are exploring changes in the roles of doctors in their relationship with patients as a result of social media use by their patients. Such approach allowed our respondents to explore their understanding of how their roles change.

We conducted in-depth interviews with general practitioners in the Netherlands. Our focus is on the effect of patient's use of social media on the roles of doctors. Therefore, general practitioners represent a good choice as they are the healthcare providers who have the most frequent interactions with patients. General practitioners are traditionally known as a "hard to reach" research population (Cunningham et al., 2015). However, we managed to conduct 19 in-depth interviews with general practitioners, which we elaborate on in the next section.

5.3.2 Data collection and analysis

In line with many studies that choose a qualitative approach, our primary ways to collect data were the interviews. As noted above, general practitioners are a hard population to reach for

research purposes (Cunningham et al., 2015). Therefore, we relied on a snowball sampling technique as we progressed with our interviews. In particular, we asked our interviewees to point us to other general practitioners who could be interviewed and provide us with new insights on the topic. Such approach is not only pragmatic, but it can also lead to emergent knowledge (Noy, 2008). We interviewed general practitioners who are employees, but also the ones who are managers of their practice. This approach to different levels (i.e. employees and practice managers) provides the basis for a more reliable theory and richer data (Eisenhardt, 1989). In order to obtain a rich amount of data, we conducted our interviews in a semi-structured way. Such an approach combines a predefined set of questions with an opportunity to improvise and explore topics during the conversation (Myers, 2009). Interviews were structured in three sections: (1) general questions related to the background and work experience of the doctors (2) roles of doctors and how they see themselves in terms of what they do (3) patients' use of social media and changes as a result of such use. Our interviews typically lasted about an hour, but some were as short as half an hour.

We approached the data analysis phase inductively with an open mind to allow the data to speak for itself (Miles & Huberman, 1994). Following the principles of the inductive approach, we coded parts of the interview that we identified as relevant for the aims of this chapter – the changing roles of doctors as the result of the social media use by their patients. After reading and re-reading the transcripts, we (re) coded the data, identifying specific terms until our coding covered the material. We applied this approach to the transcripts until we reached the codes (i.e. first order) and categories (i.e. second order), thus fully addressing the relevant information the general practitioners provided. In particular, our first phase of the data analysis included the process of theoretical coding (Glaser, 1978). In this phase, we identified instances related to the patients' use of social media, doctors' communication with patients, their work with patients, and their values in doctor-patient communication. In the next phase, we tried to bring these

findings together, which were similar (Corbin & Strauss, 1990). By doing so, we allowed cross-comparison of our findings from the different general practitioners to allow differences and similarities to emerge (Eisenhardt, 1989), which lead to the main themes we present in the findings. Table 5.1 illustrates our data analysis process.

Table 5.1. Data analysis process

Goal of analysis	Data	The process of data analysis		
		Codes	Categories	Themes
To uncover how the use of social media by patients change roles of doctors.	19 interviews with general practitioners.	Data describing roles of doctors and their communication with patients. Data describing values of doctors and link to their roles. Data describing social media.	Data indicating how their roles change in coaching patients. Data indicating how doctors start learning from patients. Data indicating how doctors move to more social-emotional aspects of the doctor-patient relationship. Data indicating how the authority of doctors becomes less important. Data indicating changes in technical tasks of doctors.	From "leading" to "coaching." From "teaching" to "learning." From "hard" to "soft." The decreased authority of doctors Less focus on technical tasks

5.4 Findings

Our findings focus on how doctors change their roles, especially vis-à-vis doctor-patient relationships. In this way, our five themes reveal the effect of social media use by patients on doctors' occupational identity in terms of "what we do". In particular, doctors now have to cope with their new role of "coach" instead of having the "leading role" they used to have. Doctors are not the only providers of medical knowledge anymore and therefore, they occasionally adopt the role of "student" to their patients instead of being a "teacher" to their patients. They do more "socio-emotional" tasks, and their actions shift from a "hard" towards a "soft" relationship. Furthermore, doctors now act with the decreased level of authority towards their patients. Finally, they reduce the focus on technical knowledge in their work with patients.

5.4.1 From "leading" to "coaching" of the patients

Whereas the traditional role of doctors could be portrayed as "leading" in their relationship with their patients, our findings suggest that this has shifted to more of "coaching". Doctors have to deal with patients that, through their use of social media, become more responsible. In particular, the patients increasingly find information on social media and change their relationship with doctors. Due to this adopted role, doctors faced more patients who took more responsibility for their health and became more proactive in their relationship with doctors asking different questions, as one of the doctors illustrated:

"They have other questions, I think. They know more about it, so they have more knowledge." (I8).

Doctors have to deal with more persistent patients due to their social media use. Regarding this change in their role, doctors explained that they face the patients who have different arguments due to their use of social media.

Doctors also perceive an increase in the level of patients' medical knowledge. Consequently, doctors describe a change in the way in which they have to consider the information collected

by patients on social media. Thus, they have to consider the information the patients bring to consultations. They also perceive patients as more persistent and responsible because they are more and better informed as the result of social media use. Consequently, doctors see the change in what they do by moving from leading the patient to coaching them on how to use this information properly. This is well illustrated by the following quote from one of the doctors:

"And what I think what I notice, what I like is that many people (patients) use me a bit as a coach. And that's what I like."(I6).

5.4.2 From "teaching" towards "learning"

In the traditional context of the doctor-patient relationship, doctors were often the only providers of medical knowledge and the sole decisions makers for patients. Therefore, doctors used to mostly "teach" their patients. Our findings show that the use of social media by patients leads to situations in which doctors change from "teaching" their patients to also "learning" from their patients. There seem to be a few main reasons for this change. Firstly, doctors now take patient's use of social media use into account. According to the doctors, patients make it known to their doctors that they are using social media to learn about their condition and exchange information with other patients. In some cases, patients are very explicit, as one of the doctors described his interactions with the patients who use social media:

"I think that a lot of people, especially younger ones, just look up what they actually suffer from. Yesterday I had a boy with a headache, and I thought why should that boy come in the afternoon? He did not have anything serious in my opinion. But he had indeed read everything on the internet and social media and he admitted it because we (me and the co-assistant) were surprised. It turns out that the boy has indeed made use of the internet and social media." (I3).

Even when patients do not make their use of social media explicit, doctors have still fundamentally changed the way they handle their consultations. They seem to hold a belief and practice of asking about patients' use of social media for health-related purposes and taking this

into account. In such cases, doctors ask patients about their use and what information they have found for their specific disease. They try to learn from it and ask patients about their social media use for health-related purposes as illustrated in the following quote:

"I start to ask how patients think and arrive at diagnosis. What about the reason they contact fellow sufferers?." (I7)

Doctors also observe that the information asymmetry between them and patients has reduced and they start to learn from patients. In particular, our interviewees indicate an increase in patients' level of medical knowledge as the result of their social media use. For example, they notice more informed questions from patients, which enables doctors to also learn from their patients. Hence, they feel that the social media based information brought by patients has increased their medical knowledge. This holds especially for the case of chronic and rare diseases.

"As a doctor you think of "how are your experiences with that", that information then comes from social media. People who have a chronic illness for ten years sometimes have a good suggestion to use some other way" (I8). "I can learn and become better" (I6).

5.4.3 From a "hard" towards a more "soft" way of working with patients

The traditional role of doctors regarding what they do reflects the intention to rely on their knowledge and medical facts in discussions with patients. This is what we refer to as a "hard" way of working with patients. However, our findings show that the "what doctors do" has also been changing in this respect. In particular, their way of working has shifted from "hard" to "soft" as the result of their patients' social media use. In this reformed way of working, the communication and role of doctors are shifting from a "one-way" mode of communicating only knowledge and facts, towards increased interactions with patients about social-emotional issues.

According to our interviewees, the patients who use social media come with straightforward questions and often seek confirmation from doctors. In particular, the patients try to discuss and verify the information they found on social media. Doctors find themselves in the situation where patients present self-developed diagnosis. However, they still need to ask the doctors about it and indicate their insecurity, which has lead doctors to focus more on social-emotional aspects in their dealings with their patients. Example quote illustrate the cases when patients look for confirmation from their doctors:

"The people who make use of social media, seek above all confirmation or disempower of their story. They have something that they have read about, but first have a look at what the doctor thinks of it." (I8)

"There happened to be somebody today who said I know what I have, I have very warm feet for few days and then I went to a patient platform and there I read this and that, but I would also like to hear your opinion on this" (I1)

However, patients do not just seek to confirm their diagnoses. Their use of social media leads to having different kinds of questions from them. They turn to their doctors to discuss their feelings of insecurity following the use of social media.

These questions are about uncertainties and self-diagnosis, which require doctors to get to know their patients better emotionally. As a result, the role of doctors is changing in the sense that the doctor-patient relationship moves from "hard" to "soft". In particular, doctors perceive patients as sometimes not able to judge the accuracy of the information they find. Thus, they raise their concerns with doctors, which has become a regular way of dealing with the patients. This has especially come from patients who feel insecure and get scared from the information they find on social media, which leads to changes in the way doctors do work with the patients, as illustrated in the quotes below:

"*They are very anxious because of social media, and therefore very quickly want to make an appointment with me, because they had seen something.*" (I3)

5.4.4 Working with patients using a reduced level of authority

The traditional work of doctors and the way they do their work has emphasized a high level of authority. Our findings indicate that the focus on this as an integral part of their identity, in terms of "what they do", is reduced. These changes are mostly driven by two findings presented earlier, which describe changes in roles of doctors in their doctor-patient relationship.

Firstly, it is the theme that portrays the changing role of doctors, who are shifting from "teaching" to also "learning". Doctors now perceive patients as having a higher level of medical knowledge than before, and thus the traditional information asymmetry has been reduced. These two mechanisms have affected doctor's level of authority in their work with the patients. Accordingly, it seems that doctor now has a lower level of authority when working with the patients. Within their traditional way of working and having the role of a "teacher", doctors exercised a relatively high level of authority. However, in their new adopted way of working and their role as a "student", they perceive the decrease in knowledge asymmetry between themselves and patients. Therefore, the way in which they act with patients as part of their daily work has been affected.

There is now a more balanced level of knowledge between doctors and patients than previously existed. As noted earlier, this is in particular reflected for the medical knowledge that concerns chronic and rare diseases. As a result of patient's increasing knowledge, doctors have experienced an increase in their knowledge, which lead to reduced levels of authority.

"I think it's great that people, at the moment they have a certain illness, that they are going to see what can be found about it. Of course I'm looking at the regular medicine, of course I know that. On those platforms, of course, there is also a lot of advice given towards the alternative

medicine and of I have no knowledge of it. Patients easily find the medical information on social media and this contributes to their higher autonomy" (I11)

Another finding that we link to this change in "what doctors do" is a shift from "leading" to "coaching". Our findings indicate that the patient's search for and sharing of medical information on social media makes them less dependent on doctors. The use of social media by patients has affected high level of doctors' authority. They experience dealing with more responsible and more persistent patients who often take the lead during consultations. Consequently, doctors have adjusted their work by acting with reduced levels of authority.

5.4.5 Reducing the level of "technical" tasks

Two findings which identify the change in the roles of doctors vis-à-vis their technical knowledge and tasks are the ones that described the shift from "teaching" to "learning" and dealing with patients in a "hard" to "soft" manner.

The traditional roles and way of working for doctors emphasized the importance of their technical knowledge and a focus on the provision of this knowledge as their guiding principle. In this way of dealing with patients, doctors were the only providers of "technical" knowledge and focused on technical tasks in dealing with patients. However, according to our interviewees, patients now have an increased level of "technical" knowledge due to their use of social media.

"People can find each other much easier, especially for rare diseases. That is a very good thing that people can easily find each other. This allows them to discuss all sorts of information and answer certain questions much easier. That is something that we also see in our practice" (I2).

As a result, doctors do not solely focus on their "technical" tasks in dealing with patients but spend more time focusing other types of tasks such as providing "socio-emotional" support. Therefore, within this new way of dealing with patients the "what doctors do" has changed in a reduction of focusing on "technical" knowledge. A recurrent theme in the interviews was a

sense of having to focus on "socio-emotional" aspects. One more important aspect of change is the reduction of information asymmetry, as doctors now also "learn" from their patients.

Another mechanism of change is that the role of doctors has shifted from "hard" to "soft" in their relationships with patients. Doctors now believe that they have to deal with an increased trend in providing "socio-emotional" support. Hence, their relationship with patients has become softer, and their patients expect more "socio-emotional" support than "technical" support. Thus, in this "soft" way of dealing with the patients, doctors are required to conduct less "technical" tasks. This trend affected what they do in the sense of increased attention to less technical tasks and increased attention to soft tasks such as reassuring their patients. In this way, the use of social media of patients has altered what they do, hence focusing more on reassuring the "socio-emotional" state of patients.

5.5 Discussion

This chapter aimed to investigate how the patients' use of social media challenged the occupational identity of doctors regarding "what they do". In doing so, we conducted interviews with general practitioners with an explicit focus on how social media changed what they do and how this affects their roles. Our findings show that the aspect of "what they do" changed in the following aspects: providing more coaching, learning more from the patients, dealing with the patients in a "softer" way, with a lower level of authority and focusing less on technical tasks. First, the role of the doctor has changed from being a "lead" person towards the role of a "coach" for patients. This is somewhat in line with what earlier literature has suggested. Van Uden-Kraan et al. (2010) proposed that the use of social media by patients has threatened the authority of doctors. Our findings enrich this literature by deepening our understanding of how what doctors do change in the light of social media. In their traditional work, doctors had the "leading" role, which was accepted by the patients. However, the use of social media by patients

created more self-managing, persistent and well-informed patients. This led to the doctors having to adopt a new role of "coaches".

The second key finding in this chapter came from revealing how the use of social media by patients has changed the work of doctors from only "teaching" their patients to also "learning" from their patients. The tradition of "what doctors do" and "how they act" with the patients, was primarily to act only as providers of medical knowledge (McMullan, 2006). However, with the use of social media, patients have full access towards medical information (McMullan, 2006; Antheunis et al., 2013). Our findings show how this has altered the doctors' work in terms of their role as teachers. In particular, the use of social media by patients has shifted the work of doctors from a traditional "teaching" role, as seen in traditional interactions with patients (Reay & Hinings, 2005). Hence, our findings indicate a change in starting to learn from the patients.

A third key finding is that doctors have changed from dealing with patients in a "hard" way to an increasingly "soft" communication with patients. The most important work of doctors in the traditional relationship was to provide objective medical information and treatment, thus engage in so-called "hard" ways of dealing with patients (McMullan, 2006). However, this chapter extends the extant literature by revealing how the use of social media by patients has shifted the work and role of doctors from a "hard" to a "soft" relationship with the patients. In particular, our findings show that patients that use social media sometimes become insecure and look for socio-emotional reassurance and support from their doctors. Thus, the amount of self-diagnosis and level of insecurity, of patients is sometimes increased by social media. By responding to this, doctors have shifted their role and begun to place more emphasis on dealing with the patients in "softer" ways. Whereas extant literature referred to patients being less

informed and less active in the relationship with doctors, our findings show a clear shift to providing more socio-emotional tasks, thus a "softer" way of dealing with the patients.

Our finding on the reduced level of authority exercised by the doctors enriches and, to some extent, contradicts earlier studies. In particular, Reay & Hinings (2005) argued that doctors have a high level of authority and make most decisions for patients. However, our finding reveals that the changes in the roles of doctors affect their behavior in this respect. In particular, doctors reduced the level of authority, and this does not represent a guiding principle in their daily work.

Our last finding concerns the reduced level of technical tasks conducted by doctors. Earlier studies have shown that doctors were the ones providing this kind of knowledge (Reay & Hinings, 2005). Our findings extend the idea of how new technologies can affect the way of work (Leblebici, Salancik, Copay, & King, 1991). In particular, changes in the roles of doctors to acting as "students" and having a "softer" relationship with patients changed what they do and the tasks they focus on. Our findings indicate that doctors have been extending their focus from mostly providing technical responses to also more social-emotional guidance.

5.5.1 Theoretical implications

This chapter deepens our understanding of changes in the work of healthcare professionals and emerging social media use in healthcare. Our findings bear implications for the literature on occupational identity and technology.

First, the literature on occupational identity covers two aspects of the identity, namely in respect of "who we are" and "what we do". However, studies have focused far less on the aspect of what we do (Irwin & Nelson, 2014). We contribute to this aspect of the literature by providing insightful findings of how the occupational identity of doctors has changed in terms of what they do. It is important to understand their occupational identities regarding "what they do"

because this shapes the way that they interact with patients, such as when they distance themselves from patients or the human side of medicine (Bonsteel, 1997).

Our second contribution to this stream of literature is related to the link with technology and occupational identity. Earlier studies found that occupational identity and the adoption of technologies are related. For example, Nelson and Irwin (2014) have shown that the occupational identity of librarians changed over time by shaping librarians' interpretations of technology. Actually, many other studies have established the impact of technologies on occupational identity (e.g. Leonardi, 2007; Irwin & Nelson, 2014). However, our findings are novel in the sense that we move from a direct effect of interactions with technology to indirect ones. In particular, we extend earlier work to show an indirect effect of technology on occupational identity. Whereas some earlier studies have focused on the direct effects of technology on occupational identity, we explore how this occurs indirectly via interactions between actors. More precisely, we have shown how the aspect of "what we do" (i.e. roles and work of doctors) has changed as a result of the indirect use of technology (i.e. social media use by patients). In particular, this chapter reveals how this indirect effect has taken place via interactions between patients, the direct users of technology, and their doctors. Although most of the literature on occupational identity has emphasized the importance of interactions, this has remained somewhat ignored (Reay et al., 2017). Furthermore, linking the indirect effects of technology use has remained scarce and primarily focused on the user-centric use of technology. Yet, a recent study by Sergeeva et al. (2017) explored how technology use is also shaped by those who are present in the room where technology is used but do not use it directly (i.e. onlookers). In a similar vein, we enriched the literature by showing how the use of new technology by one set of actors (i.e. patients) can indirectly (re) shape the occupational identity for different actors (i.e. doctors) through patients' use of technology and their interactions with the doctors.

5.5.2 Practical implications

We note that our findings bear practical implications for healthcare providers and policymakers. Being familiar with the changes in roles of doctors due to the social media use by patients, healthcare providers can communicate with their patients more effectively. By understanding the changes that new technologies such as social media may have on roles doctors, policymakers may enrich curricula for doctors, which is also in line with priorities regarding healthcare interventions via social media identified by Chou et al. (2013).

5.5.3 Future research

This chapter was focused on the subjective interpretation of general practitioners. Although doctors and medical field represent a good setting for studying the work of professionals, some of the findings could be healthcare specific as it is a distinctive and highly institutionalized field. The data were collected from general practitioners, thus reflecting their perceptions of changes. It would be useful for future research to study direct interactions and the implications of technology as well as indirect ones. In addition, future research could extend this research to other types of doctors beyond general practitioners. Furthermore, we are not able to provide a statistical generalization of our findings. Thus, future research could focus on quantitative research and test this across different professional fields.

Chapter 6: Role of the self-determination perspective in explaining the relationship between patients and their healthcare providers[5]

Abstract

The use of social media by patients may be changing the relationship between patients and their healthcare providers. We draw on the self-determination perspective to explore the effects of patients' social media use on the doctor-patient relationship. We predict that informational support obtained from other patients via social media increases patients' competence and autonomy, while emotional support via social media increases their psychological relatedness with other patients. Additionally, we propose indirect effects of these three aspects of self-determination on the relationship between patients and healthcare providers. We collected data through a longitudinal survey of 124 users of a newly established social media platform and find that emotional support, but not informational support, boosts patients' self-determinism. This may be because online informational support was already available from non-social media websites, whereas the social media platform enabled new emotional support. Interestingly, and contrary to some recent literature, we find that social media use by patients improves the doctor-patient relationship. In particular, we show that social media use by patients for informational and emotional support enhances their relationship with their healthcare providers through a change in their self-determination. Furthermore, our post hoc analysis reveals different effects between giving and receiving emotional and informational support.

[5] This chapter was written together with Albert Boonstra and David Langley.

6.1 Introduction

Healthcare consists of many healthcare actors including providers of services such as doctors, pharmaceutical companies, and patients. As such, healthcare can be seen as a system in which these actors interact to create a value (Ciasullo, Casimato, Storlazzi, & Douglas, 2016). In this system, the most important aspects are patients and their health outcomes. Accordingly, healthcare has been slowly transitioning towards so-called patient-centered healthcare (McCormack et al., 2011). One core aspect of this approach is the relationship between patients and their healthcare providers. Actually, the healthcare consultation process between patients and their healthcare providers is considered to be a cornerstone of medical practice. It represents a formalized process of interaction in which the patient seeks advice from the healthcare provider and the healthcare provider attempts to provide a solution to the patient's problem. A classic model of the consultation process by Pendleton (1984) describes tasks such as defining the reason for the visit, achieving a shared understanding of the problem and choosing the appropriate triage. This process has been traditionally characterized by face-to-face interactions between doctor and patient as the primary way to exchange information (Street, 1991). For many years other alternative sources of information for the patients such as, for example, books and other patients, were not easily accessible due to travel and mobility restrictions and outdated materials (Broom, 2005b). Thus, doctors were the primary source of information for patients (Ha & Longnecker, 2010). However, the doctor-patient consultation is often too short for the patients to get all their questions answered (Kuehn, 2011). Furthermore, although there is a strong focus to change healthcare towards a more patient-centered one, patients may still be seen as passive actors in this type of relationship (Coulter, 2012).

However, the emergence of the Internet has brought about change and patients now also turn to online sources to look for health-related information. For example, a recent *Pew Research* study shows that 72% of the Internet users in the USA searched for health information online

in 2012 (Fox & Duggan, 2013). They looked for information on conditions, doctors, treatments, procedures and ways to communicate with other patients. Many of those who search for health information online turn to social media. Social media, in particular, enable patients to communicate with each other and share health advice and information. Social media have indeed proliferated in the healthcare domain (Kane et al., 2009) and allow patients to move from one-to-one and one-to-many to many-to-many forms of communication (Hawn, 2009). In this way, patients can connect with their peers and feel supported (Lau & Kwok, 2009; Ziebland & Wyke, 2012). Hence, patients extend their traditional sources of information and interactions with friends and fellow patients (Rains, 2007).

However, with social media, patients go further and exchange health advice and build their knowledge (Antheunis et al., 2013). When patients extend their process of communication via social media to include some of the aspects that are traditionally part of the face-to-face doctor-patient interactions, this may have effects on this process (White & Horvitz, 2009). Such developments have been linked mostly to beneficial outcomes regarding health (Hamm et al., 2013). However, patients are becoming less dependent on the information that they obtain from their healthcare providers (Rupert et al., 2014). This could lead to beneficial and non-beneficial outcomes. On the one hand, patients who rely on social media for information about their condition are more satisfied with the healthcare they receive, and they may feel empowered (Da Costa et al., 1999; Househ et al., 2014). On the other hand, the use of online information could potentially lead to tensions with their doctors if patients find online information more credible than information provided by their doctors (Agarwal et al., 2010).

Social media allow new ways of interactions, which focus on consumer experiences (Hansen, Shneiderman, & Smith, 2010). In fact, through their interactions, consumers (i.e. patients) are also engaging others whom they interact with (Garretson, 2008). In this way, social media are essentially transforming such entire systems (Walmsley, 2010). In the context of healthcare,

this suggests that social media may be changing current healthcare provision, in particular, the relationship between patients and their healthcare providers as the use of social media seem to enable patients to take more active roles.

However, extant research mostly focuses on the type of use by patients categorizing informational and emotional support as two major types of use or developing propositions about potential changes between patients and healthcare providers (Antheunis et al., 2013). Thus, a theoretically driven explanation and empirical tests of the effects of informational and emotional support via social media on this relationship is lacking. This indicates a need for a deeper understanding of the impact of social media in healthcare and IS scholars call for more research on this topic (Agarwal et al., 2010; Fichman et al., 2011). To address this gap and respond to the calls, we draw on a self-determination perspective and conduct a longitudinal survey in a newly established social media platform. Self-determination perspective facilitates understanding of behaviors and it is interesting theoretical perspective to explain health-related outcomes (Ng, 2015; Ryan et al., 2008).

Hence, this chapter aims to explore the effects of social media based patient-to-patient communications on their relationship with healthcare providers. In particular, we argue that patients' use of social media for informational and emotional support will have indirect effects on the relationship between patients and healthcare providers through the concept of self-determination. We aim to contribute to health information technology literature by focusing on social media and its related effects. Furthermore, we study this from the patient's perspective whereas most studies in the health information technology domain are concerned with the doctors' perspective (Agarwal et al., 2010). Overall, we address the following research question: *To what extent does social media use by patients affect their self-determination and indirectly affect their relationship with healthcare providers?*

In addition to theoretical implications, this chapter also has practical implications for healthcare providers and policymakers. Healthcare providers can better understand how social media utilization by patients may impact the healthcare provision process, and they can adapt their behavior to better address patients' changing needs and demands. Moreover, they can gain insights into how they may become involved in this virtualized process on social media. Healthcare policymakers may use findings from this chapter to reconsider measures promoting social media utilization.

6.2 Theoretical background

In this section, we provide a brief overview of the relevant literature on social media in healthcare, the self-determination theory, and related hypotheses.

6.2.1 Social media in healthcare

We define social media as Internet-based applications built on the technological and ideological foundations of Web 2.0, which enable the creation and exchange of user-generated content (Kaplan & Haenlein, 2010). Typical social media include blogs, microblogs, social networking sites, wikis, and video or content sharing sites. Since their emergence, social media have become very popular and have changed how we communicate (Aral et al., 2013). Social media are specific in the sense that they represent end-user-driven technologies. Such technologies follow a bottom-up rather than a top-down approach in the use and adoption of technology (Boudreau & Robey, 2005). With such technology, patients can easily post and receive content as well as make connections with each other. The specificity of social media in regards to other technologies is also reflected in the social media affordances concept (Treem & Leonardi, 2012). They propose that visibility, editability, persistence, and association characterize social media communication. These principles also apply to social media health communities where patients can make their knowledge and communication known to others (visibility), they can adapt and build on each other's content (editability), they have accessible communication even

when they are not present (persistence), and they create connections with each other or with the content (associations). These distinct characteristics of social media explain how patients can easily and openly share information and are different from earlier technologies that were based on Web 1.0. For example, earlier studies discussed the patient's use of medical information on the Internet and other technologies (Josefsson & Hanseth, 2000). Yet, patients traditionally have relied on doctors for informational support, and this has been linked to outcomes such as higher reported health-related quality of life and higher self-efficacy (Arora, Rutten, Gustafson, Moser, & Hawkins, 2007).

However, social media proliferated in healthcare and offered similar opportunities (Antheunis et al., 2013). Therefore, we argue that social media can be used to provide patients with similar support. The last few years have also shown an increase in research on health-related social media. Social media are used by doctors and patients (Moorhead et al., 2013). The research covers various themes such as the features of social networking sites and health groups (Bender et al., 2012; Greene et al., 2011). Social media use by patients enables them to discuss their conditions without their healthcare providers. In particular, social media facilitate creation and exchange of health-related content with patients who have the same condition (Gómez-Zúñiga, 2012).

The common concepts of patients' use of social media in health IS literature are informational and emotional support. With social media, patients can easily provide each other with such support (Antheunis et al., 2013). For example, they can share knowledge and provide information about medications (Lederman et al., 2014). However, they can also provide emotional support to each other (Chung, 2014). We define informational support as an exchange of online health-related content, which concern general knowledge about a condition or advice on how to treat the condition (Liang, Ho, Li, & Turban, 2011). In line with this, we

see emotional support as an exchange of online health-related information, which concern expressions of understanding, empathy, and care for each other.

Such use of social media and in particular for informational support may empower patients as it provides them with the information they need to take care of themselves and explore options in regards to treatment in an easily accessible way (Househ et al., 2014). Individuals can take on a less dependent role vis-à-vis their doctors and develop their perspective on their condition based on different sources. This allows individuals to approach their condition in a more active and meaningful way, making them feel more empowered (ibid). Through the provision of informational support and the sharing of experiences by others, patients can act upon this information and develop their skills and thus become more able at treating their condition (Ruehlman, Karoly, & Enders, 2012). For example, the patient platform PatientsLikeMe has shown such potential (Frost & Massagli, 2008). In addition to the patient's use of social media and effects on their empowerment, there is limited research that concerns social media and the effects on the relationship between patients and their healthcare providers. The relationship between patients and their healthcare providers is important as it has an important effect on the quality of care patients receive (Broom, 2005). Such focus in a relationship enables doctor and patient to build mutual trust and feel good about each other (Kaba & Sooriakumaran, 2007), which should eventually facilitate effective treatment.

Social media may also influence this relationship. For example, the work of Colineau and Paris (2010) indicates that the patients could challenge doctors using the information they get from others online. Furthermore, social media use can increase the knowledge of patients and could, therefore, challenge the power of doctors in the relationship between patients and healthcare providers (Van Uden-Kraan et al., 2010). This could also affect trust as patients may reduce their trust in the information from doctors where it conflicts with the information they find via social media (McMullan, 2006). The same line of research shows that doctors sometimes react

positively to the information patients bring from social media because this enables patients to understand their doctors more easily, especially concerning medical information doctors provide to patients (Potts & Wyatt, 2002). Rupert et al. (2014) propose that social media use by patients also makes them more interested and engaged. However, as noted above, van Uden-Kraan et al. (2010) suggest that this could also challenge the traditional roles doctors have. In addition, patients do not always share the information they gather online with their doctors (Rupert et al., 2014). Accordingly, many doctors may not be aware of their patients' social media use, but the relationship could still be changing, especially from the patients' perspective. As the patients become more knowledgeable about their disease, this may lead to more in-depth discussions and in turn can facilitate shared-decision making, which is seen as one of the main characteristics of patient-centered care (Lober & Flowers, 2011). Furthermore, patients are usually more satisfied with their doctors when they have received informational and emotional support, even when this support is not necessarily from the doctor (Da Costa et al., 1999).

Overall, our literature overview indicates that there are different potential effects of social media use on the relationship between patients and healthcare providers. Hence, we are faced with conflicting explanations of changes in the relationship between patients and healthcare providers due to social media. To address this and contribute to the literature, we draw on the self-determination perspective from the psychological sciences, which we elaborate on in the next section. We argue that this use of social media by patients will affect their self-determination directly, and this will, in turn, affect their relationship with healthcare providers, thus providing a potential explanation for the conflicting results published so far.

6.2.2 Self-determination perspective

The current research draws on the perspective of self-determination to explain the outcomes of social media use (Deci & Ryan, 2000; Ryan & Deci, 2002). This perspective addresses basic human psychological needs. Consequently, it acknowledges the importance of human agency

and intentionality, as well as conditioned responses toward the social-environmental conditions. Explaining human behavior, therefore, is done through looking at personal characteristics and the environment. The three key components of self-determination are autonomy, competence, and relatedness. Achieving these is done in interaction with the social environment one engages with. Although people strive to achieve these three components of the theory in seeking their self-determination, they might not always be fully and explicitly aware of this (Deci & Ryan, 2000). Ryan and Deci (2002) use the following definitions of the three key components. Firstly, autonomy is defined as perceiving the source of one's behavior. Competence is about being able to feel effective in interactions with others and able to express one's capacities in dealing with others. Finally, relatedness represents having a connection with others in terms of caring for them and having the feeling of being cared for, thus belonging to the community.

It is an interesting theoretical perspective to explain health-related outcomes (Ng, 2015). Such outcomes are related to a patient's own motivation to engage in specific behaviors. For example, Ryan et al. (2008) propose that the satisfaction of these basic psychological needs of autonomy, competence, and relatedness would lead to improved mental health as well as improved physical health. This perspective facilitates our understanding of how one internalizes behaviors and decides to engage in a particular behavior (Ryan et al., 2008). In relation to health, this motivational theory identifies autonomy as a human need, which facilitates more autonomous forms of behavioral regulation. In this context, competence would represent a situation in which one feels effective about health-related behavior as well as being able to act competently with regards to it. Finally, a need for relatedness drives people to get in touch with others and develop a sense of belonging regardless the goals or outcomes they set for themselves. An example would be that patients with a certain condition just feel connected to others with the same condition as they are facing the same issues and problems.

6.2.3 Hypotheses development

Effects of informational and emotional support on patients' self-determination

In this chapter, we argue that informational and emotional support will directly affect individual components of self-determination and, indirectly, affect the relationship between patients and healthcare providers. In particular, we propose a direct effect of informational and emotional support on individual components of self-determination, while we expect patients' social media use to influence their relationship with healthcare providers via their enhanced self-determination. As such, we propose an indirect effect to take place through an aggregated concept of self-determination. We elaborate on specific hypotheses below.

First of all, it is expected that the extent to which patients use social media as a source of informational support will be positively related to autonomy and competence. Autonomy is facilitated if one is given access to appropriate information and provided with an opportunity to engage in discussions on treatments, thus being able to make choices about them (Williams & Deci, 2001). These behaviors are likely to be supported in social media health communities that are targeted at patients, as the aim is often to inform patients, let them share experiences, support each other and learn from each other (Antheunis et al., 2013). Such interactions enable experiential knowledge sharing and facilitate finding condition-specific information that could be useful to patients. Compared to other sources of information, social media enable patients with an opportunity to be flexible and engage in online communication at any time or from any location. In this way, they can choose when and where to interact with other patients, thus making it an effective way to communicate with each other. Furthermore, the patient needs, especially for those with a chronic disease, change over time (Van Uden-Kraan et al., 2008). Social media enable patients to adapt their behavior over a period of time as the patients can easily accommodate their evolving needs.

Social media based communication is also less controlled in comparison to a classic patient-doctor interaction, where the doctor is the one holding the information and giving the options (Rupert et al., 2014). Therefore, whenever a patient uses social media to obtain relevant information on a condition or to find support from others who will help them, we expect that this will lead to the patients' need for autonomy becoming more fulfilled. Hence, we hypothesize that both using social media for informational support will increase patients' autonomy.

Furthermore, when patients use social media for informational support, this can lead to increasingly feeling more competent. As previously established, competence means being able to engage in health-related actions. This is facilitated through one's understanding actions and being able to receive guidelines to engage into actions (Niemiec & Ryan, 2009). Some of these types of support can be found on social media. For example, patients using social media can educate each other and build expert knowledge together (Smailhodzic et al., 2015), hereby mastering the knowledge that is available about a condition. Increased knowledge about the condition facilitates patients to become more effective in treating themselves, which reflects increased levels of competence. Whereas the knowledge of patients and thus an increase in their competence can also come from other sources, social media provide them with specific features that alternative sources may not. Social media can connect patients, facilitate information sharing and collaboration, thus providing more direction in mastering their condition than other sources could. In this way, patients can find relevant and accurate information about their condition from other peers (Eysenbach, 2008). Furthermore, social media affords patients with the opportunity to narrate their experiences in different ways. For example, a study by Chung and Kim (2008) have shown that social media represent a way in which participants can share their stories, find correct information about their disease and manage some of their health issues. Thus, the informational aspect via social media does seem essential for the fulfillment of the

need for competence, as it helps individuals understand and even master the knowledge that is needed to engage in health-related behaviors. In line with this, we hypothesize:

H1a: The use of social media as a source of informational support is positively related to patients' autonomy.

H1b: The use of social media as a source of informational support is positively related to patients' competence.

Whereas we expect informational support to be linked with the competence and autonomy, we expect patients' relatedness to be affected by their use of social media for emotional support. The feeling of relatedness is felt when one has a sense of being respected and belonging. This feeling arises, for example, when someone tries to adopt another's perspective (Deci & Ryan, 2000). Social media afford patients more control and choices about how they present themselves online as well as how much they share with others about their condition. Depending on their needs, users (i.e. patients) can choose to either reveal more to others or interact more discreetly (Treem & Leonardi, 2012). This allows more anonymous interaction, which some patients may prefer. Actually, it also allows them to discuss topics they would not otherwise discuss face-to-face or with their doctors (Rodham, McCabe, & Blake, 2009). In this way, they can anonymously talk about their health and feel safe (Seeman, 2008). This increased openness may provide an easier way to create a bond with other patients who are suffering from the same condition. Furthermore, patients are flexible in mutual communication as they can do so regardless of time or location and so can feel related to fellow sufferers even on the other side of the world.

Overall, users of social media have been found to show solidarity together and to value each other. This type of support is likely to increase a sense of belonging, as one may feel connected to others who have taken the time to listen and make a person feel valued. It is a form of support that involves one person signaling understanding and a willingness to help another person,

which may increase that person's feeling of being cared for. Hence, perceived relatedness is expected to increase when patients are using social media as a source of emotional support.

H2: The use of social media as a source of emotional support is positively related to patients' relatedness.

Indirect effects of informational and emotional support on the relationship between patients and healthcare providers through patients' self-determination

Existing studies may facilitate our understanding and building of hypotheses for the relationship between patients' social media use and the relationship between patients and healthcare providers. The early research defined the concept of patients who maximize self-care knowledge, skills, and self-awareness, thus being able to make their own decisions and set goals (Anderson, Funnell, Barr, Dedrick, & Davis, 1991). As such, they may differ from traditional patients who have typically learned to adhere to their doctor's advice, similar behavior has been described by Househ et al. (2014) when patients were using social media for the informational support. Patients indeed often join social media to find informational support (Antheunis et al., 2013). As previously hypothesized, this informational support has the potential to increase patients' feelings of competence and autonomy. In turn, the fulfillment of the need for competence and autonomy may be important for influencing the relationship between patients and healthcare providers.

Through the use of social media, especially with regards to chronic diseases, the patients can learn skills to deal with their disease. Patients achieve this through engaging in health-promoting activities as well as through interacting with doctors and adhering to their advice (Heisler et al., 2002). Managing chronic diseases requires significant motivation on the part of the patient to adhere to specific treatment regimes, such as diets, or exercise programs. Through the fulfillment of the need for self-determination, people have been found to become

intrinsically motivated, which is linked to better and more stable outcomes as compared to extrinsic motivation (Deci & Ryan, 2000). Therefore, the fulfillment of these needs could be important for the ability to self-manage a disease. To illustrate this relationship: we expect a patient who uses social media as a source of informational and emotional support to feel more autonomous and competent, but also more related to his or her online peers. The fulfillment of these needs, in turn, increases this person's intrinsic motivation to manage the disease, resulting in more stable and better management of the condition, bringing about a change in the relationship with the healthcare provider. In summary, the use of social media enables patients to give and receive more informational and emotional support than they would from their doctor alone. If this is done successfully, it increases their self-determination, which in turn changes their relationship with the healthcare provider.

In particular, patients with a higher level of self-determination may engage in the type of relationship in which they make decisions together with their doctors using the best available information from the doctor and social media resources and look for the best treatment (Elwyn et al., 2010). However, this type of relationship may not be so common in healthcare provision because patients can also feel scared and unwilling to ask questions about medical concepts they do not understand (Godolphin, 2009).

Furthermore, doctors may not be used to dealing with expert patients or those confident about their knowledge of the condition. However, doctors do play an important role in having an active relationship with patients (Elwyn et al., 2010). This is particularly important for decision-making and the aid patients get from their doctors. This support is often informational and emotional as it can aid the patient in understanding more about their condition and offer an opportunity to empathize with other patients. In this respect, healthcare-related social media can be considered a decision aid as they enable patients to give and receive relevant information about the different options available to them, as well as provide them with personal experiences

of other patients. Hence, we hypothesize an indirect effect on the relationship between patients and healthcare providers as follows:

H3a: *The use of social media as a source of informational support influences the relationship between patients and healthcare providers because of a change in the patients' self-determination*.

H3b: *The use of social media as a source of emotional support influences the relationship between patients and healthcare providers because of a change in the patients' self-determination*.

Our conceptual model is presented in figure 6.1.

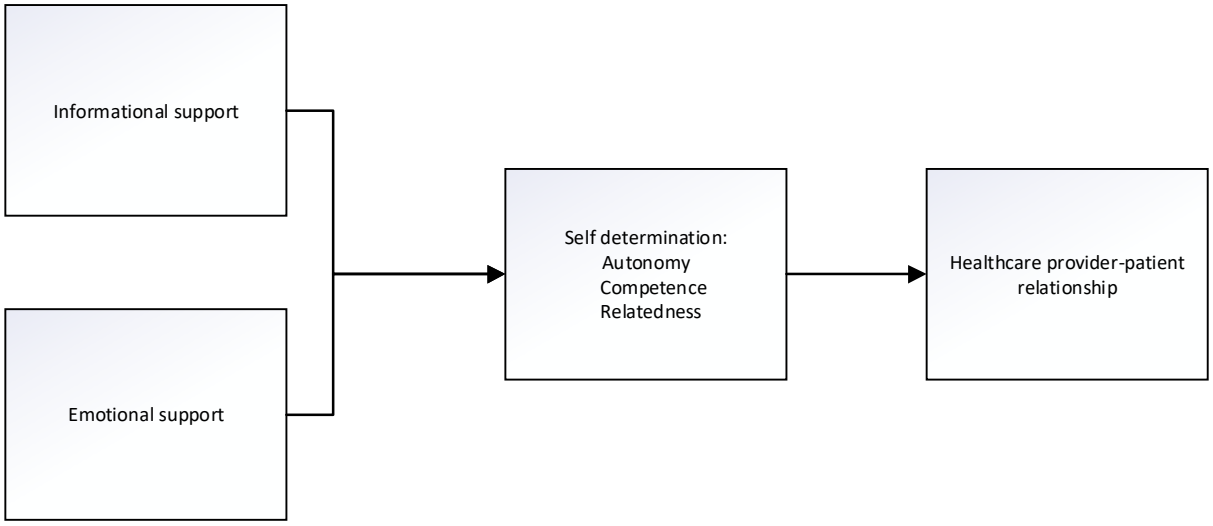

Figure 6.1 Conceptual model showing direct and indirect effects of patients' use of social media

6.3 Methods

6.3.1 Data and procedure

We tested our hypothesis in the context of chronic disease patients. In particular, we conducted a longitudinal survey amongst users of a newly established social media platform for diabetes patients in the Netherlands with over 2000 registered members. The survey was prepared with the support of Qualtrics software. This social media platform was set up by the Dutch Diabetes Association, the platform members were approached through a project leader who distributed

the survey on our behalf in April 2016. The project leader contacted patients via the social media community website and sent an email to all registered users inviting them to complete the survey. To increase the response rate in the first round, our partner (i.e. Diabetes association) offered a monetary prize to 10 randomly selected participants who completed the survey. In addition, we sent two reminders to complete the survey. This yielded 169 responses.

Following this, we approached the same group with a 2nd round survey in January 2017. We chose this timing because we considered eight months to be sufficient for patients to reach their peak use of the platform and experience any changes in the relationship with their healthcare providers. To increase our survey response rates, we offered a chance to win a tablet to a randomly selected participant, and we sent reminders. This follows good practice to achieve good response rates (Dillman, 2000). The second round of the survey resulted in a total of 124 responses from individuals that completed the survey in two rounds.

6.3.2 Measures

To measure our concepts, we relied on a 7-point Likert scale, which represents the most common method for scaling responses in survey research. With this scale, the respondents express their agreement or disagreement on an agree-disagree scale for a number of statements. Wherever possible, we used validated measures, which we adapted to fit the purpose of this research. We conducted the survey in the Dutch platform. Therefore, we translated questions to the native language of the participants and back to English to ensure appropriate translation.

Informational Support: To measure the extent to which the social media was used for informational support, we used a validated measure consisting of five items for this concept and asked respondents to reflect on their use of the platform (Shakespeare-Finch & Obst, 2011). Example items include: “Read or give information about doctors and treatments”, “I learn about treatments”.

Emotional Support: We used a validated five items measure of Shakespeare-Finch and Obst (2011) to measure emotional support. The items included statements such as "When I am feeling down, there is someone I can lean on in this platform", "This platform enables me to have a circle of people who value me".

Self-determination. To measure the concept of the self-determination, we adapted the measure of Wilson, Rogers, Rodgers, and Wild (2006), which was used to measure the self-determination in sports. In total, we had 12 questions about three concepts of the self-determination in regards to the chronic disease. Example items include: "I feel free to make my own choices in managing diabetes" "I feel that I am able to cope with my diabetes", "I feel connected to the people who also have diabetes".

Relationship between patients and healthcare providers. To measure the relationship between patients and healthcare providers, we used aggregated measure consisting of aspects covering the doctor-patient partnership, information exchange, shared decision making and trust, as they reflect the relationship between patients and healthcare providers (Lerman et al., 1990). The example statements for these constructs included: "I suggested a certain kind of medical treatment to my doctor" and "I insisted on a particular kind of test or treatment for my symptoms".

Control variables: To rule out possible biases, we controlled for type of diabetes and duration of the disease. For the type of diabetes, we recorded type one, two or other. For the duration of disease, we created five categories, namely a) shorter than six months b) between six months and one year c) one-three years d) three-five years and e) longer than five years.

6.3.3 Data analysis

First, we checked the measurement quality of the constructs. To confirm the scales' reliability, we calculated the Cronbach's alpha scores. All of our scales had values that were 0.7 or higher, which is considered to be acceptable (Hair et al., 2010). In order to check for potential problems

with multicollinearity, we checked variance inflation factors (VIF). Our values were between 1 and 2, which indicates no issues with multicollinearity as they are all well below the threshold of 10 (Hair et al., 2007).

Given the longitudinal nature of our data, we used information from round one for our independent variables. For dependent variables (i.e. self-determination and doctor-patient relationship), we used the data collected in the round two. To test our hypotheses 1 and 2, we used stepwise regression analysis. We first included our control variables in step 1 and then our independent variables in step 2. To test our hypotheses 3a and 3b, we utilized the Process procedure (Hayes, 2013) to apply a bootstrap method to estimate indirect relationships between social media use and the relationship between patients and healthcare providers via self-determination. Following the recommendations from Hayes (2013), we relied on the bootstrap sample size of 5000. We interpreted bias-corrected 95% confidence intervals to assess the conditional indirect relationships' statistical significance (Edwards & Lambert, 2007). Due to some missing values, our total sample for the regression analysis was 111.

6.4 Results

6.4.1 Descriptive statistics

Means, standard deviations, and bivariate correlations for all variables are presented in Table 6.1. As we expected, emotional support is positively correlated with relatedness ($r = .37$, $p < .01$). As expected, components of the self-determination except for competence were also positively correlated with the relationship between patients and healthcare providers. In particular, there was a positive correlation between competence and relationship between patients and healthcare providers ($r = .22$, $p < .05$) as well as relatedness and relationship between patients and healthcare providers ($r = .42$, $p < .01$). Of the control variables, only length of the disease had a positive correlation with the autonomy ($r = .19$, $p < 0.05$). However, there

was no positive correlation between our independent variable of informational support and dependent variables of competence and autonomy.

Table 6.1 Descriptive statistics.

Variable	M (SD)	1	2	3	4	5	6	7	8
1. Type of diabetes	1.56 (.65)	-	-.02	-.02	-.10	.01	.01	-.13	-.06
2. Length of disease	4.78 (.56)	-.02	-	-.01	-.03	.09	.19*	.09	-.06
3. Informational support	4.91 (1.20)	-.02	-.01	-	.63**	-.04	.01	.32**	.07
4. Emotional support	4.00 (1.38)	-.10	-.03	.63**	-	-.17	-.09	.37**	.13
5. Autonomy	5.55 (1.15)	.01	.09	-.04	-.17	-	.82**	.16	.11
6. Competence	5.53 (1.05)	.01	.19*	.01	-.09	.82**	-	.27**	.22*
7. Relatedness	4.58 (1.31)	-.13	.09	.32*	.37*	.16	.27**	-	.42**
8. Provider patient relationship	5.04 (.88)	-.06	-.06	.07	.13	.11	.22*	.42**	-

*Note: * $p<.05$; ** $p<.01$*

6.4.2 Hypotheses testing

Hypothesis 1a predicted a positive association between informational support and autonomy. However, results reported in table 6.2 indicate that there was no significant association between informational support and autonomy (B =.12, SE =.11, $p>.05$).

Hypothesis 1b predicted that social media use for informational support and competence are positively associated. As reported in table 6.2, we found no significant result for this hypothesis (B =.11, SE = .10, p >.05). Thus, our hypothesis 1b is also not supported.

In our hypothesis 2, we argued that emotional support will be positively associated with relatedness. As indicated in table 6.2, our results show a significant positive association between emotional support and relatedness (B =.25, SE = .10, p <.05). Hence, our hypothesis 2 is supported.

Hypothesis 3a suggested an indirect relationship between informational support and the doctor-patient relationship through self-determination. As reported in table 6.3, the results show that

the indirect relationship was negative and not significantly different from zero (B=-.00; 95% confidence interval = -.09 to .11). Hence, our hypothesis 3a is not supported.

Hypothesis 3b suggested a significant positive association between emotional support and the relationship between patients and healthcare providers through self-determination. Our results indicate that there is indeed a significant and positive relationship (B=.09; 95% confidence interval = .01 to .20). Our hypothesis 3b is, therefore, confirmed, as shown in table 6.4.

Table 6.2 Direct effects of patients' use of social media on the self-determination.

Predictors/Dependent Variables	*Autonomy*	*Competence*	*Relatedness*
Control variables			
Type of diabetes	.00 (.16)	.04 (.14)	-.19 (.17)
Length of disease	.19 (.19)	.36 (.17)*	.24 (.20)
Independent variables			
Informational support	.12 (.11)	.11 (.10)	.16 (.12)
Emotional support	-.20 (.09)*	-.11 (.09)	.25 (.10)*

Notes: N = 111; Unstandardized regression coefficients are shown; standard errors are noted within parentheses. * p < .05;** p <.01

Table 6.3 Indirect effects of informational support on the relationship between patients and healthcare providers.

		95%Boot confidence interval	
	Boot indirect effect	Lower bound	Upper bound
Dependent variable			
Provider-patient relationship	-.00	-.09	.11

Notes: N = 111. Based on 5,000 bootstrap samples

Table 6.4 Indirect effects of emotional support on the relationship between patients and healthcare providers.

		95%Boot confidence interval	
	Boot indirect effect	Lower bound	Upper bound
Dependent variable			
Provider-patient relationship	.09	.01	.20

Notes: N = 111. Based on 5,000 bootstrap samples

6.4.3 Post hoc analysis

Given that some of our hypotheses were not supported, we engaged in the further exploration of our data to try and understand why our hypotheses were not supported. This is, in particular, the case for our hypotheses 1a and 1b, which posited that the informational support would be

positively associated with the competence and autonomy. Traditional measures of informational and emotional support are mostly about receiving this kind of support. That also holds for our measure of informational and emotional support (Shakespeare-Finch & Obst, 2011). Due to social media, users are now able to not only receive but also give emotional and informational support. In particular, Web 1.0 was all about receiving the content whereas Web 2.0 enabled receiving and giving. To test the taxonomy that we proposed in the chapter three we also included some questions that reflected items from the taxonomy in our survey. In this way, we managed to capture some aspects of giving informational and emotional support. We then made use of these statements in out post-hoc analysis to see if we could split our items into giving and receiving of informational and emotional support. To do so, we conducted a principal component analysis that can show classification amongst a certain set of items (Hair, 2013). This helped us to see which items belong to which components. We used principal component analysis with varimax rotation. We then included the items that had factor loadings above 0.7 as they are considered to be satisfactory (Field, 2005). In this analysis, we included our original items of informational and emotional support, which reflect receiving, as well as nine items that we captured in our survey to reflect giving emotional and informational support. Our factor analysis revealed three separate components, out of which two reflected our original measures, and one was exclusively about giving. However, out of the nine items for giving emotional and informational support, two of the new items had loadings below 0.7 and were therefore excluded. This left us with three separate components, and we used seven items from a third (new) factor to create an additional variable of giving (emotional and informational support). The results of our principal component analysis are reported in Appendix F.

Following this, we conducted a regression analysis by adding this new variable to our earlier models. The results of the analysis are presented in table 6.5.

Table 6.5 Direct effects of patients' social media use on the self-determination

Predictors/Dependent Variables	*Autonomy*	*Competence*	*Relatedness*
Control variables			
Type of diabetes	.04 (.16)	.06 (.14)	-.15 (.17)
Length of disease	.06 (.20)	.24 (.18)	.10 (.21)
Independent variables			
Informational support	.07 (.11)	.06 (.10)	.11 (.12)
Emotional support	-.28 (.10)*	-.19 (.09)*	.17 (.11)
Giving	.21 (.10)*	.20 (.09)*	.23 (.10)*

Notes: N = 111; Unstandardized regression coefficients are shown; standard errors are noted within parentheses. * p < .05;** p <.01

As shown in table 6.5, when giving is added in the model for autonomy as an outcome, the relationship between giving and autonomy is positive and significant (B =.21, SE = .10, p < .05). Furthermore, in this model, the relationship between emotional support (receiving) and autonomy is also significant, but negative (B =-.28, SE = .10, p < .05).

Furthermore, in using competence as our dependent variable, we observed two significant relationships. In particular, we observed a positive and significant relationship between giving and competence (B =.20, SE = .09, p < .05). Furthermore, just as in the case of autonomy, we also observed a negative and significant relationship between emotional support and autonomy (B =-.19, SE = .09, p < .05).

For our third dependent variable, we observed that giving has a positive and significant relationship with relatedness (B =.23, SE = .10, p < .05). However, we also observed that the positive relationship between emotional support and relatedness is not significant anymore in the model 3 when giving is added (B =.17, SE = .11, p > .05).

6.5 Discussion

Our aim in this chapter was to explore the effects of increasing social media based communications of patients on the relationship them and their providers. In particular, we proposed that the mechanism through which the patients' communication on social media

affects the relationship between patients and healthcare providers is the concept of self-determination. On the one hand, we hypothesized that the patients' use of social media for informational support would positively affect their feeling of competence and autonomy. On the other hand, we hypothesized that the use of social media for emotional support would positively affect their feeling of relatedness. Furthermore, we hypothesized that the informational and emotional support would affect the relationship between patients and healthcare providers through an increased sense of the self-determination.

Our findings have shown several key findings. We first discuss findings from our hypotheses, then we engage in the discussion of our other findings, which were not hypothesized but emerged from our post-hoc analysis.

Firstly, in our hypotheses on the role of informational support, we proposed that the informational support patients obtain on social media would directly affect patients' feeling of competence and autonomy (H1a and H1b) and indirectly through the self-determination the relationship between patients and healthcare providers (H3a). We found that the use of social media for informational support affected neither the autonomy nor the competence of patients. In line with this, we did not find evidence to support the theory that informational support indirectly affects the relationship between patients and healthcare providers. This is a somewhat surprising result given that the extant literature repeatedly related the informational support with patients being more knowledgeable, and thus also more competent and autonomous in their managing of the disease. For example, the rising role of social media has been considered as a new and important media in which users (i.e. patients) create and share the knowledge together (Karakas, 2009). In line with that, extant literature strongly focused on the role of informational support and strengthened knowledge, which increases the competencies of patients. This was through participation in online health discussions that strongly improved the knowledge and competence of patients, which even allowed them to sometimes self-manage

their disease (Ruehlman et al., 2012). Furthermore, such patterns in knowledge building were in particular observed for diabetes patients, especially deriving from reading about the experiential knowledge of others (Chen et al., 2011). The same holds true for autonomy where extant literature proposed that when the patients receive informational support, they feel more autonomous (Entwistle & Watt, 2013; Gustafson et al., 2008). In particular, Gustafson et al. (2008) proposed that the receiving of informational support could increase competence and autonomy by giving patients the feeling that their knowledge and abilities are increased. However, earlier literature also found that this is not always the case. For example, (Warner et al., 2011) have shown that although informational support increased the feeling of autonomy for patients who had a low level of self-efficacy, it threatened the feeling of autonomy in patients with high levels of self-efficacy.

One possible explanation for not finding the support for our hypotheses on the role of informational support could be due to the differences between social media and Web 1.0. Given that we studied a newly established social media platform, we believe that the informational needs of the patients could have been already filled through other means before the launch of the new social media platform, such as Web 1.0 sites offering one-to-many healthcare information. For example, it could be possible that these patients learned about managing diabetes earlier on Web 1.0 and shifting to Web 2.0 did not add much to the informational side. Secondly, we found support for our hypotheses on the role of emotional support (H2 and H3b). Specifically, that patients' use of social media for emotional support directly increased the relatedness of the patients as well as indirectly affected their relationship with healthcare providers through stronger feelings of self-determination. Social media indeed create new opportunities and offer a different process of communication than other technologies (Fox, 2011). In particular, social elements enabling users to connect with each other through sharing and modifying content was not present in Web 1.0 As such, it creates different ways to look for

online health information than just browsing the Internet, it offers more collaborative and engaging opportunities (Hesse et al., 2011). Users can provide each other with emotional support via social media (Malik & Coulson, 2010). In such situations, relating to others becomes a more important part of the process (Boulos & Wheeler, 2007). This could explain why our results show a direct effect of emotional support on patients' feeling of relatedness (H2), while the direct effects of informational support on autonomy and competence were not supported. In regards to the effect of emotional support on the relationship between patients and healthcare providers, earlier studies have mostly emphasized the concept of informational support as the one that could affect the relationship between patients and healthcare providers (Colineau & Paris, 2010; McMullan, 2006; Van Uden-Kraan et al., 2010). However, we have shown that the emotional support indirectly affects the relationship between patients and healthcare providers. We can conclude that within the eight months that the participants were using the platform, their self-determination grew, and this influenced how they interact with their healthcare providers.

In addition to the results from our hypotheses, our post hoc analysis and findings on non-hypothesized relationships also provide some new insights. In particular, we added the component of "giving informational and emotional support" as many to many communications enables receiving and giving on social media. Our original scales captured only receiving. Earlier research has shown that there is a difference in motivation between those who contribute (contributors) and those who just receive (lurkers). Thus, we added this dimension to our analysis. From our regression results, we observed that, when 'giving' was added to the analysis, the emotional support was actually negatively related to autonomy and competence. This suggests that increased levels of receiving emotional support may lead to dependence on such kind of support, eventually negatively affecting autonomy.

Another interesting finding emerged from our post hoc analysis when we added a third independent variable (i.e. giving). Specifically, we considered a need to make a distinction between giving and receiving informational and emotional support. However, in our exploratory factor analysis, giving on its own was shown as one factor, which suggests that giving emotional and giving informational support are highly related. The key finding in this respect was that giving to others had significant and positive effects on all sub-concepts of self-determination (autonomy, competence, relatedness). This was above and beyond the concepts of receiving emotional and informational support, which have been covered in the literature (Broom, 2005b; Gómez-Zúñiga, 2012; Rupert et al., 2014).

It is possible that through giving, patients actually improve learning and realize how much knowledge and expertise they have. For autonomy, an explanation may be that by giving, the patients become less dependent on others and more aware of their knowledge and abilities. For relatedness with others, the patients may be feeling more related to each other as giving to others implies that they take an active part in the relationship with other patients in the community.

Furthermore, as noted in previous paragraphs, this could be because social media indeed create new opportunities and offer a different process of communication than other technologies (Fox, 2011). In particular, social media also enable others to give informational and emotional support and not only receive. Whereas this has not been the primary focus of this chapter, it deserves further attention in future research.

6.5.1 Theoretical implications

Our findings bear implications for literature on healthcare and health information technologies as well as literature on social media.

We contribute to the health information systems as lead IS scholars have called upon research in this context (Agarwal et al., 2010; Fichman et al., 2011). In this respect, our findings bear

implications for the relationship between patients and healthcare providers and the respective roles of emotional and informational support within this relationship. First of all, we have provided a clear finding that the relationship between patients and healthcare providers is altered due to the use of the social media platform and that this change has come about through the patients' self-determination. Additionally, the indirect effect of social media use on this relationship is caused by emotional but, surprisingly not by the informational support received on social media. In addition, we have shown that the relationship is actually improved.

Interestingly, earlier studies have emphasized that it was mainly informational support that would alter the relationship between patients and healthcare providers. In particular, these studies suggested that the use of social media for informational support would challenge doctors. For example, Agarwal et al. (2010) proposed that giving more credibility to the information from other patients on social media could create tensions in the relationship between patients and healthcare providers. In line with this, earlier work on Internet use by patients has suggested that such use can harm the relationship of patients with their doctors (Kim & Kim, 2009). Furthermore, it was explicitly proposed that through the informational support, patients would challenge their doctors (Van Uden-Kraan et al., 2010). Accordingly, this could also affect the trust as part of the relationship between patients and healthcare providers, as patients may reduce their trust in the information provided by doctors where it conflicts with the information they find via social media (McMullan, 2006). There appears to be a feeling from the doctors that when patients gain knowledge and empowerment through the use of social media, they will be less open to advice from their doctors, more skeptical of the information provided by doctors, and be less likely to agree with the treatment suggested (Rupert et al., 2014).

This research thus adds to this stream of literature by clearly indicating that the relationship between patients and healthcare providers improves as a result of social media use through an

increase in the self-determination. Specifically, and somewhat surprisingly given the extant literature, this takes place through increased emotional support. One possible explanation is that patients enter into the doctor-patient interactions more as equals and worthy partners in the management of their condition than ever before. This then changes the nature of the dialogue, allowing for full sharing of ideas, concerns, and options. Whereby the two sides of the relationship together decide on the most appropriate course of action, which could promote a more patient-centered approach to healthcare process (McCormack et al., 2011). This is somewhat contrasted to the traditional relationship in which doctors are seen as knowledge owners and decision makers (van den Broek et al., 2014).

Our findings also bear more general research implications for the field of information systems with a particular emphasis on social media. The research on communications within digitally enabled environments such as social media has been increasing (Faraj et al., 2011; Vaast, Safadi, Lapointe, & Negoita, 2017). This stream of literature has often explored how such communications leads to different outcomes. For example, Treem and Leonardi (2012) have shown how the use of social media increases knowledge sharing and building in organizations. Other studies such as Ogink and Dong (in press) have shown how this communication takes place in the process of stimulating innovation. In doing so, extant literature strongly focuses on the role of informational support and knowledge sharing in this context (Faraj et al., 2011). This is somewhat understandable given the focus of these communities on aspects such as knowledge and innovation (Faraj et al., 2011; Ogink & Donk, in press). Yet, there seems to be less focus on the role of emotional support and relatedness of users in such social media communities. Thus, our research adds to this by showing the importance of emotional support and feeling related to others in the community, which, also had a stronger influence than informational support did.

Furthermore, we have briefly explored the relative importance of giving and receiving on social media. Whereas earlier literature does not make a clear distinction between receiving and giving on social media, our post hoc analysis has shown how distinct giving is compared to receiving, and how strong its effects are on self-determination. In our case, this could be explained by the differences between Web 1.0 and social media (Web 2.0). In particular, the Web 1.0 could only be used for reading/receiving and not giving. Yet, social media enable both actions. In the case of our patients, we show in our post hoc analysis that giving seems to lead to all outcomes of the self-determination (autonomy, competence, relatedness) whereas receiving reduces self-determination.

Hence, we add to extant research on social media by showing how making a distinction between giving and receiving could play a significant difference. This particular finding requires future research.

6.5.2 Practical implications

From a practical perspective, this research provides insights into what it means for the relationship between patients and healthcare providers when patients use social media as a source of emotional and informational support. Patients and other stakeholders could benefit from these insights. Patients could benefit by understanding that their engagement and participation in social media communities could not only relate them to others, but also enhance their relationship with doctors. In the same line, doctors and other healthcare providers could benefit, not only by understanding the implications that the use of social media by their patients, but also by potentially offering their own social media communities with the focus on emotional support, which could then indirectly through the relatedness enhance their relationship with the patients. Other actors for whom this could bear implications are insurance companies. Specifically, building on these insights and offering patients an opportunity to engage into social media communities with the focus on emotional support could bring benefits given that

the patients' relationship with doctors improves and could thus to lead to better health outcomes.

6.5.3 Future research

We used an aggregated measure for the relationship between patients and healthcare providers, which covers some aspects of the interactions doctors and patients engage in. Future research is needed to explore the different elements of doctor-patient interactions. In addition, it could assess how each element is affected by a higher level of patient self-determination due to their use of social media. Furthermore, our research is limited to testing the effects of social media use on the self-determination and indirect effects of this use on the relationship with doctors. However, further research is required to explore other effects of patients' increased self-determination on the wider healthcare system, beyond the relationship between patients and healthcare providers. We speculate that once the traditional identity of doctors changes and more of a coaching role is adopted, the consequences will be far-reaching. This may include several aspects of the healthcare provision system. Finally, our post hoc analysis has shown a distinction between giving and sharing. Thus, future research can focus on further exploring this difference and related effects in healthcare.

Chapter 7. Discussion

In the discussion of our research efforts and their implications, we first present our main findings and address the research questions from each of the chapters. Following this, we discuss the theoretical and practical implications of our findings. Finally, we propose a future research agenda as a follow up of this research, particularly about the transformative role of social media. Findings presented in the dissertation bear implications for healthcare information technology literature, but also for broader IS literature. Thus, in the discussion of our theoretical and practical implications as well as future research, our discussion goes beyond the context of healthcare.

The main goal of this dissertation was to explore the role of social media in healthcare, particularly their transformative role for patients and healthcare professionals. In our chapter two, we set out to address the research question: *What are the effects on patients from their use of social media and how does this influence their relationship with healthcare professionals as reported in extant literature?* To address this research question, we conducted the systematic literature review. The chapter has identified that patients are using social media mostly for social support, namely informational and emotional aspects of this support. However, we identified other types of use such as social comparison. In this chapter, we also reviewed the effects of such use of social media on patients themselves and on their relationship with healthcare professionals. In this respect, the findings were mixed, as the use of social media by patients seem to have positive and negative effects on patients and on their relationships with healthcare professionals. For example, whereas some patients felt improvements in their well-being and self-management of the disease, others experienced negative outcomes such as reduced well-being and loss of privacy. We came across the same findings for the relationships with healthcare professionals. On the one hand, the use of social media by patients sometimes led to more equal and harmonious relationships with healthcare professionals. On the other

hand, it also sometimes resulted in an increase in patients' switching between doctors and in a degraded relationship with healthcare professionals. One of the issues that emerged from this review was our finding that there is a lack of literature discussing differences in social media categories and their effects on the relationship between patients and healthcare providers. In addition, there was also lack of literature from the IS field focusing on these issues despite the calls within the IS community for research on these topics (Agarwal et al., 2010; Fichman et al., 2011).

In chapter three, we addressed the research question: *What are the typical interactions in health-related social media and how can we categorize them in taxonomy?* In line with the identified lack of scholarly attention to different categories of social media and patients' interactions identified in chapter two, we conducted a mixed method research covering all categories of social media (Kaplan & Haenlein, 2010). In this chapter, we identified five typical archetypes of interactions that the patients engage in on health-related social media. In particular, we identified that discussions are focused on resolving personal health condition, knowledge building through teaching, informing one another about healthcare products, empathizing with fellow sufferers, and supporting an adapted lifestyle. Moreover, we were able to categorize these types of interactions in a taxonomy based on two dimensions, namely type of control and generativity of interactions. Furthermore, two interesting findings in this chapter are that specific types of interactions take place on specific categories of social media and that there is a pattern in the type of actors who participate in particular interactions. As an illustration of this, our findings revealed that the interactions about informing one another about healthcare products occurred mostly on blogs and always had user-to-user conversations whereas the interactions about resolving personal health conditions mostly took place on social networking sites and involved user-to-user as well as provider-to-user conversations.

In chapter four, we explored how the use of social media by patients afforded changes in their roles and their relationship with doctors, especially in the context of chronic disease patients. Specifically, we addressed the research question: *How does social media use by chronic disease patients afford changes in their identity and their roles in relation to healthcare providers?* In this chapter, we conducted an in-depth netnographic study of two social media health communities, namely with the focus on diabetes and brain injury patients. The findings of this chapter have shown that the patients' use of social media afforded changes in their roles and relationships with their healthcare providers. In particular, we found that social media helped patients to reshape their roles by moving from understanding their condition to being understood by others, and by engaging in collective learning from experiential knowledge. Another significant finding was that the use of social media afforded a change in the relationship with their healthcare providers through getting silently empowered. This was by either substituting or complementing offline healthcare provision and by new collaborations and partnerships with doctors. Interestingly, we also observed social media to afford a strengthening of the identity for diabetes patients, while a (re) construction of identity was observed in brain injury patients. Furthermore, we also observed differences vis-à-vis changes with healthcare professionals with regards to general practitioners and specialists, specifically general practitioners were more affected by these changes than specialists.

In chapter five, we set out to out to investigate how the use of social media by patients affect what their doctors do. In particular, we tackle the research question on the indirect effect of patients' use of social media on the occupational identity of doctors with a focus on the "what they do" aspect, thus addressing the research question: *How does the occupational identity of doctors in terms of "what we do" change as a result of social media use by patients?* To address this research question, we conducted in-depth interviews with general practitioners. Our findings show that doctors have actually changed with respect to "what they do" as a result of

social media use by their patients. Specifically, our findings indicate that doctors now coach instead of lead patients, they also learn from patients instead of just teaching them, they become softer in the way they work with patients, they apply a reduced level of authority, and they focus less on technical tasks. Overall, our findings have revealed the change in their occupational identity, in particular related to the "what they do" aspect, especially with regards to the relationship with their patients.

In chapter six, we drew on the psychological perspective of self-determination to explain changes in the relationship between patients and their healthcare providers. Specifically, we addressed the research question: *To what extent does social media use by patients affect their self-determination and indirectly affect their relationship with healthcare providers?* In particular, we hypothesized that the patients' use of social media for emotional and informational support would increase the components of their self-determination and indirectly affect their relationship with healthcare providers. Our main findings in this chapter were that emotional support, as opposed to informational support, increased the relatedness of patients and thus the self-determination, which indirectly affected the relationship with healthcare providers in a positive way. Surprisingly, we found no support for the hypothesis that informational support increased the competence and autonomy of patients or indirectly affected the relationship with healthcare providers. To explain this, we conducted a post hoc analysis to investigate potential differences between giving and receiving informational and emotional support. Interestingly, we observed that giving, not receiving, either informational or emotional support increased the self-determination of the patients.

7.1 Theoretical implications

In this section, we elaborate on the research implications of our chapters, particularly for two streams of the literature within IS, namely social media and new technologies, and healthcare information technologies.

7.1.1 Social media and new technologies

Our research bears several implications for extant literature on social media. First, our research adds to the literature on social media use and categories of social media (Kaplan & Haenlein, 2010). Concerning social media use, our findings bear implications for the often overlooked role of emotional support and relatedness as well as the lack of distinction between giving and receiving on social media. Extant literature on social media has often focused on opportunities that social media offers regarding knowledge sharing (Treem & Leonardi, 2012). In particular, this literature places emphasis on members exchange of information and providing each other with informational support (Faraj et al., 2011), which can eventually lead to outcomes such as innovation (Majchrzak, Cherbakov, & Ives, 2009). Accordingly, the mechanisms developed to theorize how people use social media for knowledge sharing tend to focus on the informational support among social media users (Majchrzak, Faraj, Kane, & Azad, 2013). Thus, the existing strong focus on informational support and knowledge sharing overlooks the aspects of emotional support and relatedness between social media users. Our findings in this respect have implications for developing future research in this direction. In particular, our findings have shown that an integral aspect of social media communities is an exchange of emotional support and strong relatedness between users, which may lead to stronger outcomes than informational support. In this way, we enrich this stream of literature by (re) emphasizing the importance of emotional aspects and relatedness.

Furthermore, some of our findings show a potentially important distinction between giving and receiving on social media. Most studies take a somewhat implicit assumption that social media use consists of giving and receiving, without making a distinction between the two (Johnston, Worrell, Gangi, et al., 2013; Oh, Animesh, & Pinsonneault, 2016). Even when some studies assume that there is a difference, they assume that giving and receiving on social media lead to same outcomes and do not operationalize them separately, thus assuming social media use

implies both (Yan & Tan, 2014). However, our findings indicate the importance of giving on social media. Thus, our finding bears implications for extant research on social media in making an explicit distinction between the two and their outcomes.

We have also identified that different categories of social media can play an important role in types of interactions that take place on social media. This finding has implications for extant literature that does not explicitly discuss differences and similarities of social media categories. However, we have shown that the specific types of use are strongly related to different categories of social media. In this respect, we contribute to propositions for future research of social media transformative potential, especially in raising the questions on how different designs of social media affect user interactions and what categories of social media could work best for organizations (Aral et al., 2013). In line with this, our findings show that closer attention should be paid to addressing the link between categories of social media and types of interactions. Furthermore, our findings complement a potential reorganization of the taxonomy of social media categories (Kaplan & Haenlein, 2010) to reflect this link.

Our second implication for the social media literature concerns the changing roles of users and its' effect on the relationship with others, as well as an indirect change in the behavior of others. As opposed to Web 1.0, Web 2.0 social media based technologies enabled users to easily not only consume but also to create and share content with others. Our findings show that this change has not only enabled users to further understand and collaborate with peers on social media, but it has also enabled them to be understood by others and change their roles of passive content consumers to active participants.

Our findings bear some implications for the study of information technologies and identity, which has attracted increasing attention in IS literature (Carter & Grover, 2015). In addition to previous studies that focus on different technologies and their impact on roles and identity (Lee, Lee, & Lee, 2006; Mosse & Byrne, 2005; Schwarz & Watson, 2005), we contribute to the

emerging focus on new technologies such as social media (Vaast & Levina, 2015). In addition to a focus on social media as bottom-up and user-driven technologies, our research has shown interesting findings in regards to the link between how different features of social media communities and related affordances can differently impact roles and identities of users. In particular, we add to the literature by observing differences in strengthening versus (re) constructing identity. With this, we reemphasize the point made by Davison and Martinsons (2016) on valuing the context in IS research, in our case regarding of the social media community and disease specificity.

In regards to this stream of literature, our findings also bear implications for research that focuses on the roles and identities of professionals. Our chapter five that focuses on changes in roles and identities of professionals have implications for studying new technologies and their indirect effect on professionals. Our findings on indirect impacts of technology are important for future research on the use of social media on occupational identity in respect of "what we do". We extend this stream of research to focuses on the "what we do" aspect of occupational identity. In particular, we contribute to the increasing attention on the role of new technologies on the "what we do" aspect of occupational identity (Nelson & Irwin, 2014). Furthermore, our findings bear implications on the indirect effect of technology use on the changing roles of professionals. Our findings have shown that the "what we do" of professionals has changed as a result of other users' use of social media. This indicates the importance of interactions between actors through which changes in roles and identities take place. Whereas interactions are an integral part of this change, their importance has been surprisingly overlooked by the literature (Reay et al., 2017).

In addition, our findings also have implications for the literature that focuses on the user-centric use of technology and related outcomes. Until now, this stream of literature has focused mainly on users' view of technology and the effects this use has on them independent of others (Chu

& Robey, 2008; Mazmanian, 2013). Our findings add to this research by demonstrating that in addition to the direct effects of technology on the user, its use also has indirect effects on others. Similar to Sergeeva et al. (2017), we extend this user-centric approach to technology use and its related effects. Whereas Sergeeva et al. (2017) looked into the impact of others on the use of technology (i.e. onlookers), we considered the indirect effect of technology use on other actors.

Lastly, some of our findings may have implications for extant research on social media that draws on affordances perspective. Treem and Leonardi (2012) developed four affordances of social media use in organizations, which can be applied in contexts outside organizations and work environments (Fox & Moreland, 2015). These are namely visibility, persistence, editability, and association. Our findings bear implications for this stream of studies, particularly for the affordances of visibility and association with regards to the role of social media type and context, since our findings have shown that the affordances may vary per social media community. In particular, this holds implications for further studying the affordances of visibility and association. Treem and Leonardi (2012) suggest an association of the affordance that represents an association with the content. However, we have shown a distinction between the affordances of association on the content and people depend on the features of the social media community.

7.1.2 Healthcare information technology

Throughout this dissertation, we make a case for a transformative role of social media in healthcare. In this respect, we first extend traditional views and the focus of existing literature regarding healthcare information technology, which has strongly focused on topics such as electronic healthcare records and privacy (Romanow et al., 2012). We then extend our research also to include new social media technologies in healthcare. In doing so, we show that patients' use of social media, in particular, brings about changes not only for themselves but also for

their providers. It is thus suggested that future research focus on new technologies as enablers for digital transformation (Hwang & Christensen, 2008), in particular, the transformative potential of social media (Aral et al., 2013). In line with this, we take the patients' perspective, whereas most of earlier literature in HIT stream of literature has not done so (Agarwal et al., 2010).

Second, our research can serve as a framework for the exploration of different uses of social media by patients. Extant literature about the use of online sources for health-related purposes by patients has strongly focused on informational and emotional support. Our research goes above and beyond this. In particular, we suggest that the concept of informational support is multidimensional and should be taken as such. We also identify a new type of use, namely lifestyle support, whereas earlier studies have focused solely on social support (Bartlett & Coulson, 2011; Bauer et al., 2013; Menon et al., 2014). Our findings on the types of interactions on social media may also have implications for future research with regards to different categories of social media. Our findings show that certain types of interactions prevail on specific categories of social media.

Third, our research raises important questions about the effect of patients' use of new technologies on their relationship with healthcare providers. Thus, we directly contribute to the calls in IS field for conducting more research on social media in healthcare (Fichman et al., 2011). Three of our chapters focus on this aspect from different perspectives and indicate that patients' use of social media changes their roles, but also changes their relationship with healthcare providers. Although doctors are often challenged as a result of social media use by their patients, positive outcomes such as new partnerships and collaborations, have also been found. This somewhat contradicts previous studies which have suggested that patients' use of social media could only create tensions between doctors and patients (Agarwal et al., 2010) or challenge them (Rupert et al., 2014). Until now, the research has suggested that that online

sources for informational support would challenge and negatively affect the relationship between patients and healthcare providers. However, our findings do not fully support these earlier propositions. Actually, one of our findings indicates that emotional support and relatedness with other patients has positive contributions to the relationship with healthcare providers. As such, emotional support through social media may lead to even more positive outcomes than informational support (Yan & Tan, 2014). Whereas only a few studies (i.e. Yan & Tan, 2014) have indicated this potential difference for patients' outcomes, our implications are in regards to the relationship between patients and healthcare providers and call for a more elaborate approach in studying social media and its effects on the relationship between patients and healthcare providers.

Last, our research contributes and holds implications for the study of chronic conditions in the context of information technologies on which scholars called for more research, especially related to patients (Wilson & Strong, 2014). Yet, extant literature in health information technology has not paid enough attention to the importance of differences between chronic diseases although the type and nature of each chronic condition can affect patients differently (Macdonald et al., 2016). Our findings have indeed shown that there are differences exhibited by different chronic diseases vis-à-vis the relationship between new technologies and patient identities. This bears implications for future studies on the use of new technologies in the context of chronic diseases and its related effects on the relationship between patients and healthcare providers.

7.2 Practical implications

In this section, we discuss implications for users and organizations in general as well as in an overall healthcare context.

First, individual users of social media can better understand how a specific type of interactions may be easier to find and engage in on different categories of social media. For example, one

of our findings suggests that reviews of healthcare products are most often presented in blogs. Thus, our findings help individual users to orientate themselves better when looking for conversations to join on social media. Furthermore, our finding that giving seems to matter more than receiving implies that the users may gain more when they are active contributors rather than behaving as lurkers in social media communities. As for the patients specifically, they can better understand the types of social media and interactions to engage in depending on their needs. Furthermore, they can understand potential pitfalls with using social media for health-related purposes, such as developing social media addiction or having a negative experience (Malik & Coulson, 2010). Furthermore, our findings, in particular from chapter four suggest that the use of social media may be helpful in different ways depending on their stage of the chronic disease.

Second, our findings bear some implications for organizations and professionals on two aspects. Organizations can better organize their use of social media and better understand the customers' use of social media and effects this may bring about when they are aware of the link between social media features and interactions (Aral et al., 2013). As we have noted before, our findings reveal some of these links between social media types and type of interactions. Thus, these findings can help organizations to design their social media platforms better and offer features that would suit customers in the best way possible. Furthermore, organizations and professionals, such as doctors, can understand how the use of social media by customers (i.e. patients) can affect their relationship. Moreover, they can understand potentially different changes in the relationship with their clients based on the type of social media and interactions they engage in. For example, given that social media communities are increasingly being used to improve innovation efforts (Ogink & Dong, 2017), organizations can pay attention not only to informational aspects such as knowledge sharing, but also emotional aspects and relatedness between members of the community. This is, in particular, an implication of our finding in the

healthcare context that emotional support and relatedness between the members of social media community had a stronger effect than providing each other with information and knowledge only. In healthcare specifically, doctors can understand that social media may not necessarily be challenging their power and potentially creating tensions (Agarwal et al., 2010), but actually improving the relationship and creating new partnerships with patients. Furthermore, they can understand how the use of social media by their patients can positively change their role. Thus, doctors can equip themselves with the knowledge that social-emotional aspects of the relationship between patients and healthcare providers could be increasingly more important than a straightforward diagnosis and knowledge exchange.

7.3 Future research

As emphasized earlier in this chapter, this dissertation attempts to make a case for a transformative role of social media in healthcare. However, we believe that our research and practical implications provide broader insights for non-healthcare contexts, especially for future research on the transformative potential of social media for businesses, which has been noted as an important avenue in IS and business research (Aral et al., 2013; Yoo, 2013). Thus, we further make the case that future research on social media should focus on its transformative role and propose to move from individual effects of social media that we have seen to more organizational effects, especially from the user-driven social media communities.

In particular, we mean transformative potential that new technologies, especially bottom-up user-driven technologies such as social media can have for the organizations. In fact, given some recent empirical evidence that suggests that the social media even redefine entire industries such as news publishing and retail (Byers et al., 2012; Karimi & Walter, 2015), we imply that the social media can be considered to be a disruptive innovation. Disruptive innovations have a potential to disrupt existing and create new markets, displacing existing technologies (Christensen, 1997). Disruptive innovation theory posits that new disruptive

technologies get introduced by entrants who intentionally compete with incumbents. At first, entrants offer an inferior product or service. Eventually, they rise, and established incumbents get pushed out of the market. Given these characteristics of disruptive innovation, one can indeed consider that social media as a disruptive innovation.

However, social media are specific in the sense that they represent end-user-driven technologies. Such technologies follow a bottom-up rather than top-down approach in the use and adoption of technology (Boudreau & Robey, 2005). In particular, social media initiatives follow this bottom-up approach (Kaganer & Vaast, 2010). In this way, social media enable cooperation and creation of products, services, and ideas amongst individuals without the hierarchical control of firms. This implies a different pattern path of innovation and firms have to react to unknown phenomena (Kaganer & Vaast, 2010). Hence, new digital "disruptors" such as social media may affect businesses and disrupt markets in unplanned and unintentional ways (Dewan & Ramaprasad, 2014; Downes & Nunes, 2013). In this respect, future research could focus on these aspects, especially given the little research on social media in the context of disruptive innovation (Laurell & Sandström, 2014).

In particular, we could suggest designing a study to explore if and how organizations respond to disruptive threats. This could be done for example through making scenarios for managers of organizations on what user initiated social media communities are versus firm initiated communities and explore how they respond to the different source of threats. Given the threat that new technologies increase uncertainty, an interesting perspective for future research would be to look into the responses of organizations from an information processing perspective (Tushman & Nadler, 1978). With this perspective, organizations can act in two ways when faced with uncertainty, and thus respond either via buffering or bridging strategies (Bode, Wagner, Petersen, & Ellram, 2011). With buffering, firms develop buffers to reduce the effects

of uncertainty or to increase their information capacities to reduce uncertainty. With the bridging, firms reduce uncertainty by increasing their information processing capacities.

This line of future research can also be applied to healthcare. Specifically, Hwang and Christensen (2008) proposed to disrupt healthcare as we know it by shifting it from the so-called solution shops, which represent traditional business models in healthcare, to facilitated user networks. Hwang and Christensen (2008) describe the solution shop model as a traditional one where interactions between doctors and patients represent a primary way to exchange information and decide on a course of action. However, facilitated user networks representing platforms can facilitate the reciprocal exchange of information and care among healthcare actors. In this way, Hwang and Christensen (2008) suggest that such networks enable easy transfer of knowledge from specialists to generalists and onwards to healthcare users themselves. We argue that a significant enabler of these facilitated user networks are social media user communities. Thus, future research could explore mechanisms through which social media enable this and if there is the difference in categories of social media and the related interactions enabling this shift to a new business model in healthcare. These issues could be explored through the in-depth study of cases such as PatientsLikeMe and diabetics platform dLife, which have begun with enabling this shift.

In addition to the potentially disruptive role of social media proposed above, we suggest future research further investigate the differences between the two types of participation in social media communities, namely giving and receiving. This has not been the primary focus of our studies, however, in our last empirical chapter we observed a significant difference between the two. In particular, our finding that giving leads to better outcomes than receiving may be interesting for future research, especially given that most social media users are lurkers (Phang et al., 2015).

Given that this was not our main focus and it emerged as a finding from our post hoc analysis in chapter six, we would, first of all, propose a more focused study on this topic. In addition, it would be good to conduct it in multiple contexts in addition to healthcare. Whereas we applied survey research design in studying this, we would propose future research to have a design, which could be more insightful in explaining causal mechanisms. Given the abundance of social media communities, we would suggest running a field experiment with two groups of users each assigned to either the condition of receiving information or giving information on social media and related outcomes on the outcomes such as performance. Next to healthcare, a good and an insightful context for this would be educational institutions to see if giving versus receiving on social media education-related sites would lead to differences in learning outcomes.

Somewhat in line with the above, we would also suggest future research to look into the importance of emotional support and relatedness in crowdsourcing communities. As noted earlier, extant research strongly emphasizes informational support and knowledge sharing in these communities, which lead to creativity and innovative outcomes. As our findings have shown in a healthcare context, it would be insightful for scholars and practitioners to understand the role of emotional support and relatedness in these communities and related outcomes. Specifically, we would suggest extending current studies in this respect.

Furthermore, to further test the differences of use of emotional and informational support on health-related outcomes, we would suggest a different research design and a study outside of the diabetes context. For example, we would suggest running a field experiment with first-time pregnancies in women. This would provide researchers with an opportunity to design two social media communities with a different focus, namely emotional and informational support, and randomly assign participants to one of those communities. We would suggest this study with first time pregnancies as such participants would most likely be exposed to social media health-

related content on pregnancies for the first time. Such study could be done in cooperation with midwife practices and with consent from the participants. It would be insightful in the sense that it would provide clear casual mechanisms in different effects on patients as well as their relationship with healthcare providers.

Chapter 8. References

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Chapter 9. Samenvatting

Dit proefschrift onderzoekt de transformatieve rol van sociale media voor patiënten en hun professionals in de gezondheidszorg. Sociale media bieden manieren voor patiënten om te communiceren op een manier die de sterke expert-cultuur van de medische praktijk uitdaagt. Dit gebeurt door patiënten de mogelijkheid te bieden online gezondheidskennis te creëren en uit te wisselen.

Er zijn echter een aantal belangrijke hiaten in onze kennis. Ten eerste gaat bestaand onderzoek niet in op hoe of voor welke doeleinden verschillende soorten sociale media worden gebruikt. We onderzoeken het gebruik van sociale media in een interessante sector: namelijk de gezondheidszorg. Bovendien ontbreekt onderzoek over de effecten van sociale media op gebruikers zelf en op hun relaties met professionals, in dit geval de zorgaanbieders. In lijn hiermee is ons onderzoek gericht op het verkennen van het gebruik van sociale media door patiënten, de bijbehorende effecten op patiënten en hun gedrag, op hun relatie met hun zorgaanbieders en op zorgverleners zelf. We voeren een systematische literatuurstudie en vier empirische onderzoeken uit, waarover we hieronder nader ingaan.

In hoofdstuk één introduceren we het proefschrift en vatten we de belangrijkste bevindingen van de verschillende onderzoeken samen. In hoofdstuk twee gaan we dieper in op het onderzoeken en beantwoorden van de onderzoeksvraag: *wat zijn de gevolgen voor patiënten van het gebruik van sociale media en hoe beïnvloedt dit hun relatie met beroepsbeoefenaren in de gezondheidszorg, zoals gerapporteerd in bestaande literatuur?* Om deze onderzoeksvraag te beantwoorden, voeren wij een systematische literatuurstudie uit. Deze studie identificeert dat patiënten sociale media voornamelijk gebruiken voor sociale ondersteuning, namelijk de informatieve en emotionele aspecten van deze ondersteuning.

We identificeren echter ook andere soorten gebruik, zoals sociale vergelijking. In dit hoofdstuk bespreken we de bevindingen over de effecten van dergelijk gebruik van sociale media van patiënten zelf en op hun relatie met beroepsbeoefenaren in de gezondheidszorg. In dit opzicht zijn de bevindingen gemengd, omdat het gebruik van sociale media door patiënten zowel positieve als negatieve effecten op de patiënt zelf lijkt te hebben en op hun relaties met beroepsbeoefenaren in de gezondheidszorg. Als voorbeeld is te noemen dat sommige patiënten verbetering in welzijn en zelfmanagement van hun medische toestand ervaren, maar anderen juist negatieve gevolgen zoals verminderd welzijn en verlies van privacy ervaren. Er zijn vergelijkbare bevindingen met betrekking tot de relaties met beroepsbeoefenaren in de gezondheidszorg.

Dezelfde studies concluderen dat het gebruik van sociale media door patiënten soms leidt tot meer gelijkwaardige en harmonieuze relaties met professionals in de gezondheidszorg. Het resulteert echter soms ook in een toename van wisseling in artsen door de patiënt en in een aangetaste relatie met beroepsbeoefenaren in de gezondheidszorg. Onze conclusie is dat er een gebrek aan literatuur is over verschillende soorten sociale media die de relatie tussen patiënten en zorgverleners beïnvloeden.

In hoofdstuk drie stellen en beantwoorden we de onderzoeksvraag: *wat zijn de typische interacties in gezondheidsgerelateerde sociale media en hoe kunnen we deze categoriseren in taxonomie?* In lijn met het geconstateerde gebrek aan wetenschappelijke aandacht voor verschillende categorieën van sociale media en de interacties van patiënten die in hoofdstuk twee worden geïdentificeerd, voeren we een mixed-methodestudie uit die alle categorieën van de sociale media bestrijkt, behalve voor virtuele werelden. In dit hoofdstuk identificeren we vijf archetypen van interacties die de patiënten aangaan op gezondheid gerelateerde sociale media. In het bijzonder identificeren we de volgende vijf archetypen: het verbeteren van de persoonlijke gezondheidstoestand, kennisopbouw door middel van educatie, elkaar informeren

over producten binnen de gezondheidszorg, empathie met lotgenoten en ondersteuning van levensstijl. We categoriseren dit soort interacties in een taxonomie op basis van twee dimensies, namelijk het type controle en de generativiteit van interacties.

Deze dimensies zijn belangrijk omdat ze het vermogen van sociale media om interacties te genereren (generativiteit) en het soort communicatie tussen patiënten en met zorgverleners (reikwijdte van controle) weerspiegelen. Op deze manier kunnen we de potentiële effecten van deze interacties op offline relaties met zorgverleners beter begrijpen. Wij concluderen dat er specifieke soorten interacties plaatsvinden op specifieke categorieën van sociale media. Ook zien we dat er een patroon is in het type actoren dat deelneemt aan bepaalde interacties. Ter illustratie hiervan laten onze bevindingen zien dat de interacties die volgen op het archetype "elkaar informeren over producten binnen de gezondheidszorg" vooral voorkomen op blogs zoals E-patiënt Dave en patiënt-tot-patiënt-gesprekken hebben, terwijl de interacties over "het verbeteren van de persoonlijke gezondheidstoestand" meestal plaats vinden op sites voor sociale netwerken zoals Medhelp en betrekken patiënt-tot-patiënt gesprekken tussen zorgverleners en patiënten.

In hoofdstuk vier onderzoeken we hoe het gebruik van sociale media door patiënten veranderingen in hun gedrag en hun relatie met artsen mogelijk maakt. Het onderzoek richt zich vooral op patiënten met chronische ziekten, dit doen we omdat de identiteit van chronische zieke patiënten kan worden beïnvloed door hun aandoening. Concreet richten we ons op de onderzoeksvraag: *hoe kunnen sociale media die door patiënten met chronische ziekten worden gebruikt, veranderingen in hun identiteit en rollen met betrekking tot zorgverleners doorvoeren?* In deze studie voeren we de studie uit van twee sociale gezondheidscommunity's te weten één voor patiënten met diabetes en één voor mensen met hersenletsel.

De bevindingen van dit hoofdstuk hebben aangetoond dat het gebruik van sociale media door de patiënten veranderingen in hun rollen en relaties met hun zorgverleners mogelijk maakt. In

het bijzonder kunnen we concluderen dat sociale media patiënten helpt hun rol te veranderen van het begrijpen van hun eigen gesteldheid naar begrip van anderen en door collectief te leren van de ervaringen van anderen. Een andere belangrijke bevinding is dat hun gebruik van sociale media een verandering in de relatie met hun zorgaanbieders mogelijk maakt. Dit gebeurt door het vervangen of aanvullen van offline gezondheidszorg door nieuwe samenwerkingen en partnerschappen met artsen. Interessant is dat we ook zien dat sociale media de identiteit van diabetespatiënten versterken, terwijl een (her)constructie van identiteit wordt waargenomen bij patiënten met hersenletsel. Bovendien merken we ook op dat huisartsen meer beïnvloed worden door deze veranderingen dan specialisten in termen van bijvoorbeeld substitutie versus aanvulling van offline gezondheidszorg.

In hoofdstuk vijf gaan we na hoe het gebruik van sociale media door patiënten invloed heeft op het handelen van artsen. In het bijzonder pakken we de onderzoeksvraag aan: *Hoe verandert de beroepsidentiteit van artsen in termen van 'wat we doen' als gevolg van het gebruik van sociale media door patiënten*? Om deze onderzoeksvraag te beantwoorden, houden we interviews met huisartsen. Onze bevindingen tonen aan dat artsen hun identiteit veranderen met betrekking tot "wat ze doen" als gevolg van het gebruik van sociale media door hun patiënten. Concreet wijzen onze bevindingen erop dat artsen hun patiënten nu coachen om een actieve rol te spelen in de verantwoordelijkheid van hun medische toestand, in plaats van patiënten te instrueren. Ze leren ook van patiënten in plaats van ze alleen maar te instrueren. Ze passen een verminderd niveau van autoriteit toe en ze richten zich minder op technische taken terwijl andere minder technische taken dergelijke sociaal-emotionele ondersteuning aan patiënten vergroten. Over het algemeen laten onze bevindingen zien hoe de verandering in hun beroepsidentiteit plaatsvindt, vooral met betrekking tot de relatie met hun patiënten.

In hoofdstuk zes gebruiken we het psychologische perspectief van zelfbeschikking om veranderingen in de relatie tussen patiënten en hun zorgverleners te verklaren. Specifiek hebben

we de onderzoeksvraag behandeld: *in welke mate beïnvloedt het gebruik van sociale media door patiënten hun zelfbeschikking en heeft dit indirect invloed op hun relatie met zorgaanbieders?* We veronderstellen dat het gebruik van sociale media door de patiënten voor emotionele en informatieve ondersteuning hun autonomie, competentie en verbondenheid zou vergroten en daardoor hun relatie met zorgverleners zou beïnvloeden.

Onze belangrijkste bevindingen in deze studie zijn dat emotionele ondersteuning, in tegenstelling tot informatieve ondersteuning, de verwantschap tussen patiënten en dus de zelfbeschikking vergroot, wat op zijn beurt de relatie met zorgverleners op een positieve manier beïnvloedt. Verrassend genoeg vinden we geen steun voor de hypothese dat informatieve ondersteuning de competentie en autonomie van patiënten vergroot of indirect de relatie met zorgverleners beïnvloedt. Om dit uit te leggen, voeren we een post-hocanalyse uit om potentiële verschillen te onderzoeken tussen het geven en ontvangen van informatie en emotionele steun. Interessant is dat we vaststellen dat het geven, niet ontvangen, ofwel informatief of emotionele steun, de zelfbeschikking van de patiënten verhoogt.

Over het algemeen onderzoeken we de transformatieve rol van sociale media voor patiënten en zorgverleners. Onze bevindingen hebben zowel theoretische als praktische implicaties. Theoretisch dragen we bij aan de literatuur over informatiesystemen op sociale media en het effect van deze technologie op de relaties van organisaties, evenals op de literatuur over informatietechnologieën voor de gezondheidszorg. Praktisch gezien heeft ons onderzoek implicaties voor gebruikers en organisaties in het algemeen en in een algemene gezondheidszorgcontext. Onze bevindingen helpen individuele gebruikers om zich beter te kunnen oriënteren binnen de gezondheidscommunity's. Ook geeft het de gebruiker de informatie dat informatie geven belangrijker is en meer brengt dan informatie ontvangen op sociale media. Organisaties en professionals, zoals artsen, kunnen begrijpen hoe het gebruik

van sociale media door klanten, in dit geval patiënten, hun relatie kan beïnvloeden en welke rol ze moeten vervullen.

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Edin Smailhodzic

Groningen, September 2018

Appendices

Appendix A. List of databases

The databases marked in Italics were excluded from the search.

Web of Science

1) Web of Science Core Collection
2) Biological Abstracts
3) Data Citation Index
4) KCI-Korean Journal Database
5) MEDLINE
6) SciELO Citation Index

EBSCO

1) Academic Search Premier
2) AMED - The Allied and Complementary Medicine Database
3) *America: History & Life*
4) *American Bibliography of Slavic and East European Studies*
5) *Arctic & Antarctic Regions*
6) *Art Full Text (H.W. Wilson)*
7) *Art Index Retrospective (H.W. Wilson)*
8) *ATLA Religion Database with ATLASerials*
9) Business Source Premier
10) CINAHL
11) Communication & Mass Media Complete
12) *eBook Academic Collection (EBSCOhost)*
13) *eBook Collection (EBSCOhost)*
14) *EconLit*
15) ERIC
16) *GreenFILE*
17) *Historical Abstracts*
18) *L'Année philologique*
19) Library, Information Science & Technology Abstracts
20) MEDLINE
21) *Military & Government Collection*
22) *MLA Directory of Periodicals*
23) *MLA International Bibliography*
24) *New Testament Abstracts*
25) *Old Testament Abstracts*
26) *Philosopher's Index*
27) PsycARTICLES
28) *PsycBOOKS*
29) *PsycCRITIQUES*
30) PsycINFO
31) *Regional Business News*
32) *RILM Abstracts of Music Literature*
33) SocINDEX

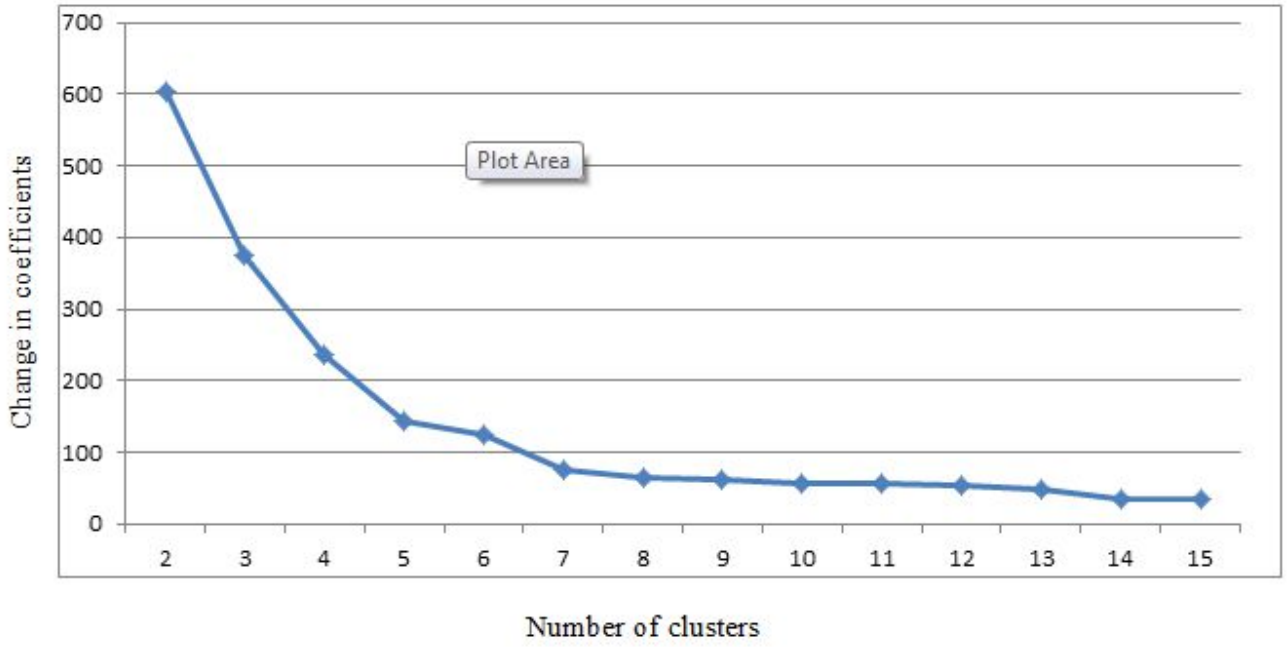
Appendix B. List of cases

	Initiator	
	Provider-initiated	User-initiated
Platform General/Specific		
Blogs		
General	Harvard medical blog	E-patient Dave
Specific	James Hamblin	Diabetes Mine
Social Networking Sites		
General	Boston Children's Hospital	Medhelp
Specific	Dr. Eisenberg	Lose weight Jo!
Content communities		
General	Everydayhealth	BeautifulBrwnBabyDol
Specific	Endobariatric	Patient power
Collaborative projects		
General	WikiDoc	Natural Health Wiki
Specific		Street Medic Wikia
Virtual Game Worlds		
General	Vitalis Island STBBI Clinic	
Virtual Social Worlds		
General	Lil Angels Maternity	First Health Hospital
Specific	Krystal's Therapy	G.Y.M. Body & Fitness

Appendix C. List of codes

Thematic code	Definition
Health condition	Conditions that indicate lack of health due to illness and/or injury.
Healthcare provider	Focusing on physicians or/and hospitals, insurance companies and other types of healthcare providers
Health product	Discusses certain health products (drugs, dietary products, etc.) and their effects
Health policy/procedures	Concerning government healthcare policy and discussions about the decisions, initiatives, plans and procedures aimed at achieving the society's healthcare goals
Suggesting offline contact	Explicit question/suggestion for offline contact with a healthcare provider
Product recommendation	Recommends or promotes certain products or services to others
Lifestyle	Concerns a style of living not necessarily related to a disease. Often relates to the topics such as exercising, eating and weight loss, skin/hair treatments
Emphatizing	Acknowledges the importance of a person and his/her personal experiences. It can be a simple 'Thank you' or emotional or inspirational type of content
Non-health	Not related to our analysis and usually spammed messages.
Nature of communication	**Definition**
Social-emotional	Contents that represent the mental state of individuals.
Instrumental	Content wherein the intention is to transfer information in an objective and explicit way
General	General discussions on particular health-related topics
Personal	Content that relates to somebody's situation, such as their health experiences
Asking	Asking others for information or opinion
Expressing	Expressing one's content or opinion
Healthcare user	It represents patients, a family of patients or other persons who are not healthcare providers.
Healthcare provider	It represents healthcare providers such as doctors and nurses.

Appendix D. Cluster analysis elbow effect



Appendix E. Details of data analysis

Phase	Aim	Data	Data analysis procedure			
			Theoretical coding	Analytical induction	Statistical analysis	Finding
1	To uncover initial topics and nature of communication.	1727 quotes	Nine codes describing the topic/theme of interactions. Six codes describing the nature of communication.	Initial idea on archetypical interactions.	N/A	Initial review of different types of interactions between healthcare actors.
2	To identify archetypical interactions.	1566 quotes	N/A	N/A	Cluster analysis and ANOVA to refine archetypes and help with interpretation.	Five archetypical interactions and differences between them.
3	To place archetypical interactions in a taxonomy	Five archetypes		We engaged in the iterative process looking at our codes, archetypes and ANOVA results and assessed the archetypes on dimensions of the scope of control and generativity.	N/A	Five archetypes placed in 2x2 taxonomy.

Appendix F. Factor analysis

	Component 1	Component 2	Component 3
Giving1	.873	.081	.021
Giving2	.668*	.288	.167
Giving3	.752	.243	.072
Giving4	.836	.095	.139
Giving5	.690*	.075	.148
Giving6	.730	.227	.167
Giving7	.713	.181	.157
Giving8	.756	-.097	.428
Giving9	.771	.274	.182
Info support1	.112	.817	.349
Info support2	.148	.786	.251
Info support3	.225	.758	.163
Info support4	.212	.857	.211
Info support5	.153	.614	.217
Emo support1	.181	.284	.789
Emo support2	.276	.273	.787
Emo support3	.349	.408	.635
Emo support4	.138	.165	.840
Emo support5	.092	.398	.754

Notes: * = deleted item